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# North Dakota Needs and Feasibility Assessment for a Statewide Family-To-Family Network

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NORTH DAKOTA NEEDS AND FEASIBILITY ASSESSMENT  
FOR A STATEWIDE FAMILY-TO-FAMILY NETWORK

by

Laurie Betting  
Bachelor of Science in Physical Therapy  
University of North Dakota, 1998

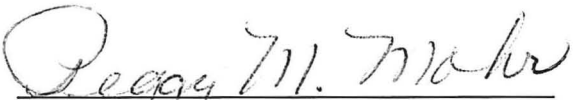
An Independent Study  
Submitted to the Graduate Faculty of the  
Department of Physical Therapy  
School of Medicine  
University of North Dakota  
in partial fulfillment of the requirements  
for the degree of  
Master of Physical Therapy

Grand Forks, North Dakota  
May  
1999

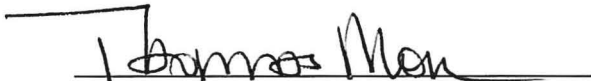




This Independent Study, submitted by Laurie Betting in partial fulfillment of the requirements for the Degree of Master of Physical Therapy from the University of North Dakota, has been read by the Faculty Preceptor, Advisor, and Chairperson of Physical Therapy under whom the work has been done and is hereby approved.

  
(Faculty Preceptor)

  
(Graduate School Advisor)

  
(Chairperson, Physical Therapy)

## PERMISSION

Title            North Dakota Needs and Feasibility Assessment for a Statewide  
Family-to-Family Network

Department    Physical Therapy

Degree        Master of Physical Therapy

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Signature Raunie Betting

Date 12/11/98

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The problem with an acknowledgment page is just that—it is a page, and it is incomprehensible to believe that all those involved will be given that credit that they so truly deserve. All the members of the Family Involvement Subcommittee with their vision and commitment gave birth to this project. Thus, it is only fitting that this project is dedicated to those families who live lives of integrity, tolerance, and commitment, and who reach out to share those qualities with other families. That is what family support is all about.

It has been said that it takes a couple of “psycho-maniacs” to get a family network off the ground. My life has been touched and changed forever by one of them, Donene Feist.

I wish to thank Peggy Mohr whose passion for excellence and dedication to reaching out to those in need has made a significant impact on me professionally and personally. Your energy, enthusiasm, and expertise continue to drive the implementation of North Dakota’s Family-to-Family Network.

To my sons, Peter and Tyler, I am deeply grateful for your patience and tolerance as we have achieved this goal together.

Finally, above all, I wish to bear witness to God’s mercy and his way of life.



## ABSTRACT

The purpose of this study was to determine the need and feasibility of a family-to-family network within the state of North Dakota. The model for this family support network would include a process of matching experienced or “veteran” parents or a family member who has a child with a disability with parents or other family members who are just beginning to meet the challenge of a disability within the family.

The research was designed to determine priorities of families with children with disabilities as well as effective methods of recruitment, referral, and training. Furthermore, the research identified agencies and programs within North Dakota that were currently providing family support services as well as opportunities for interagency collaboration. Data were obtained through the use of survey instruments distributed to agencies/providers working with families with children with disabilities ages birth through eighteen. Additionally, families with children with disabilities were involved in focus interview discussion groups to identify the needs and design of a family support network.

While there are a variety of programs and agencies within the state of North Dakota which provide certain family support services, there does not exist an organized, coordinated, statewide family-to-family network or process for systematically matching experienced “veteran” parents of a family member with a

disability with new parents or family members who are just beginning to meet the challenges of a disability within their family. Agencies/providers and families with children with disabilities agree that the need exists and that the implementation of a statewide network would be beneficial for both families and providers.

## CHAPTER I

### INTRODUCTION

*When my third daughter was born with Down Syndrome, isolation was what I felt despite being surrounded by supportive people at the time of her birth and diagnosis – the medical people who dealt with us were very sensitive; my husband and close family were incredibly helpful; our friends were trying desperately to understand what had happened – through the first few weeks I felt isolated from the very people who were trying to reach me the hardest. I felt desperately that no one, absolutely no one, knew what I was going through.<sup>1</sup>*

Families that learn that their child has a disability often experience overwhelming emotions.<sup>1</sup> Parents may feel guilt, anger, depression, and confusion and have limited resources on which to draw. Families who have a member with a disability must not only cope with the typical demands of family life, but also deal with the demands that mark the transition from the culture of the nondisabled to that of the disabled. In this process, they are faced with a host of issues about the disability itself and what it means for the individual as well as the family. In order to survive, the family must learn the languages of the

medical, legal, financial, and special education worlds. These service systems may or may not offer appropriate support opportunities. Those they would expect as familiar supports, such as relatives and friends, may distance themselves out of fear of the unknown or lack of understanding.

Societal trends, such as increased mobility and decreased interdependence, mean that extended family members often live in communities miles, if not states, away from each other. Single parenting or living in a rural environment can further alienate the family and add to the challenge of raising a child with a disability. These challenges will not disappear but rather compound themselves as the family deals with transition between service settings. Families struggle with the uncertainty of not knowing what is around the corner. When families of children with disabilities are asked who would be best to support them emotionally, they often mention other parents who share their experiences, but finding a family with a similar story is often difficult.<sup>2</sup> This is where a family-to-family network program has the potential of providing meaningful emotional and informational support during difficult periods of adjustment for parents, children, and family members. The growth of parent-to-parent support networks, such as Pilot Parents, attests to the effectiveness of experienced parents of children with disabilities helping other parents.<sup>3</sup>

As reported by Gallagher et al.,<sup>4</sup> a support network is a powerful tool for accomplishing these tasks, for teaching coping skills, and for supporting the family in a way that is responsive to their unique needs. Furthermore, they

indicated that formal and informal social support networks are important to these families, often more so than professional support, which has been uneven.

Health care professionals are not always available or able to help families learn how to function in their new roles. Additionally, many parents must work through feelings of confusion, denial, anxiety, guilt, anger, and depression. Parents of children with disabilities need opportunities to vent feelings and move forward in their own way and at their own pace in a nonthreatening, nonjudgmental environment.

According to Santelli et al,<sup>5</sup> professionals themselves often feel inadequate because they cannot truly understand what families are going through since they have not actually experienced what the families have experienced. These authors suggest that families need to be treated as having individual needs that require individual solutions. Furthermore, these authors report that health care professionals tend to focus on the multiple needs of the child with disabilities while the needs of the family are neglected. Yet, because of the importance of the family to the child, this results in neglect of the child's most important resource.<sup>6</sup>

### Problem Statement

A request for proposal (RFP) dated March 14, 1997, invited bids to research: *The Need and Feasibility of a Family-to-Family Network within the State of North Dakota*. It was understood, from the RFP, that a family support network would include a process of systematically matching experienced parents of a family member with a disability with "new parents" who are just beginning to

meet the challenge with this one-to-one relationship intent on providing both support and information.

The parents of the Family Involvement Subcommittee, who are themselves parents of children with disabilities, inspired this research. This committee is a subcommittee of the North Dakota Interagency Coordinating Council (NDICC) which is an advisory board to the Developmental Disabilities Unit and, ultimately, the North Dakota Department of Human Services. Earlier survey research completed by the Family Involvement Subcommittee, at the North Dakota Early Intervention Institute in March of 1996, supported the need for a Family-to-family network and the need for additional research.

Peggy Mohr, Ph.D., P.T., University of North Dakota School of Medicine (UNDSOM) Department of Physical Therapy, and Linda Olson, Ed.D., Assistant Director of Curriculum Development, UNDSOM Office of Academic Affairs, responded and were awarded the \$35,000 contract to conduct this research project. Laurie Lacrosse-Bruggeman, a parent of a child with a disability and a student in the Physical Therapy program at the University of North Dakota, completed the research component as fulfillment of her Independent Study requirements. A parent advisory committee in collaboration with the Family Involvement Subcommittee of the NDICC guided this research.

#### Significance and Purpose of Study

If determined feasible, the results of this study would be the foundation for the development of a three-year plan for the implementation of a family-to-family network. This study, therefore, has three purposes. The first purpose is to

determine the priorities of families of children with disabilities in regard to a family-to-family network and identify the most effective methods of recruitment, referral, and training. The second purpose is to identify programs and agencies currently providing family support and opportunities for interagency collaboration. Thirdly, the research should identify potential funding sources for the implementation of such a network.

### Research Questions

1. What are the priorities regarding the need for a family-to-family network; effective mechanisms for implementation?
2. What programs/agencies currently provide family-to-family networking?
3. What opportunities for interagency collaboration and potential funding sources exist?

To answer these questions for the service providers, a survey was created and distributed to agencies and support groups identified as providing services to families with children with disabilities within North Dakota. Additionally, focus interviews with parents of children with disabilities were conducted across the state.

The null hypothesis is that there is not a significant need for a statewide family-to-family network within the state of North Dakota. This lack of need is based on the rationale that existing programming is sufficient or there is a lack of interest, as identified by service providers/agencies or families with children with disabilities.

## CHAPTER II

### LITERATURE REVIEW

Krauss and Giele<sup>7</sup> maintain that to effectively assist families, one must meet three specific needs of families with children with disabilities: (1) information about the child's disability; (2) advice about using the service system; and (3) emotional support. Through a parent-to-parent program, parents are able to address all three needs as well as share in similar life experiences. Additionally, parent-to-parent support programs have the capacity to support the role of the professional as well as supporting the family.

The literature on family support documents ways in which families of children with disabilities are particularly qualified to help each other.<sup>8</sup> The fact that more supportive social networks are associated with better personal well being, more positive attitudes, and more positive influences on parent-child play opportunities and child behavior and development is also supported in the literature.<sup>9</sup>

#### Parent-to-Parent Programs

Parent-to-parent programs involve matching a parent of a child with a disability in a one to one relationship with a parent who is just beginning to face the challenges of raising a child with a disability. Parent-to-parent programs



differ from other parent support groups in that the match is on a one to one basis rather than in a group setting.

Training of the veteran parents, according to Scott and Doyle,<sup>10</sup> prepares family members to provide informational support, whereas life experiences enable them to provide emotional support. In most programs, veteran parents are trained to communicate effectively with parents recently informed of their child's disability. In their training, they learn that grief plays a significant role in adjusting to being parents of such a child. They also learn to make referrals to community resources.<sup>11</sup> The fact that veteran parents are trained before being matched can be an important feature in establishing the program's credibility in the community.

Veteran parents are not counselors, not therapists, and not adversaries to other support systems. Matching of parents is based on similar disability and family issues and each match evolves according to the needs and preference of the new parent. Oftentimes, the telephone is the mechanism of communication allowing an informal, flexible, spontaneous, and individualized relationship.

Martha Blue-Banning,<sup>12</sup> a new parent, described the outcome of a one to one match:

*What is making the biggest difference for us right now is having a connection with another family that has "been there before." It sure is comforting to know that even though it is new territory, at least it's not "unchartered!" The Turnbulls have been there for us to share our challenging moments, to help us reframe, even to laugh*

*when the going gets tough. We have learned from their vision for Jay. They have helped us to revise and stretch our vision for Ryan and, most importantly, they have helped us to realize our vision can come true. We have learned from their mistakes and their successes. We know that we aren't having to "reinvent the wheel." Our questions create less stress for us because we know we have a partnership, someone with whom we will find the answers. It is such an incredible feeling to realize that we are not in this alone, it makes it all seem so much more doable.*

This process of sharing helps the new parent gain confidence and adjust to life with their disabled child, while the veteran parent grows from meeting a need that might have gone unmet, allowing each parent to gain something valuable.<sup>13</sup> Mutual support groups are powerful and constructive ways for people to help themselves and each other. The basic dignity of each person is expressed in his or her capacity to be involved in a reciprocal exchange. It is this reciprocal exchange that is the core of family-to-family networks.<sup>5</sup>

Commonality of child and family characteristics often forms the basis for the match. Such factors include age of the child who has the disability, type and severity of the disability, family size and form, ethnicity, educational background, socioeconomic status, and geographical location.

The new parent may prefer a match based on the severity of the family member's disability.<sup>14</sup> When a child's disability fluctuates or the progress is irregular, the need for support may also fluctuate.

### Historical Perspective

The first Parent-to-parent program, termed Pilot Parents, was launched in 1971 in Omaha, Nebraska. A parent of a young child with Down's syndrome collaborated with two professionals and developed a model for parent support.<sup>1</sup> This model included mechanisms for (a) handling referrals and making matches; (b) recruiting, screening, and training veteran parents; and (c) providing follow-up support to each match. Other parents and professionals who wanted to replicate the Pilot Parents program were able to receive training and technical assistance from the Omaha program. Regional programs evolved into statewide programs and some states launched statewide programs at the onset.

The Beach Center on Families and Disabilities at the University of Kansas collects data on the number and scope of parent-to-parent programs.<sup>15</sup> As of 1997, there were over 500 active local and 28 statewide programs providing one to one matching to over 35,000 parents nationally. This parent support model is also prevalent in countries outside the United States, particularly in Canada, Australia, New Zealand, England, and Denmark.<sup>16</sup> Although the one to one match is the foundation of Parent-to-parent programs, some offer a variety of matched opportunities such as couple to couple, family-to-family, sibling to sibling, grandparent to grandparent, and even provide opportunities for those with the disabilities to connect. Options for additional support activities include

on-going training and consultation support for veteran parents, group activities for parents and/or other family members for informational or educational support, group activities for families, advocacy, leadership training, and training for other professionals in the community.<sup>17</sup>

### National or International Parent-to-parent Networks<sup>18</sup>

#### Mothers United for Mutual Support (MUMS)

MUMS is a national Parent-to-parent organization for parents or care providers of a child with disability, or health condition. The mission is to provide support to parents in the form of a networking system that matches them with other parents with children with the same or similar condition. MUMS' database includes over 12,000 families from 36 countries, covering over 2300 disorders, some of them very rare conditions. Matchmaker, a quarterly newsletter, allows families to share and speak out about issues affecting their lives. An annual subscription fee is charged, \$10.00 for parents and \$20.00 for professionals. Parent matching is free.

#### National Father's Network

Funding from the U.S. Maternal and Child Health Bureau supports the National Father's Network. The U.S. Department of Health and Human Services has declared fathers "an underserved population." Since 1986, this program has provided training for more than 30,000 family members and caretakers throughout the United States, Canada, and New Zealand. DADS, a bi-yearly newsletter, is produced and written by fathers; in addition, a monthly column appears in Exceptional Parent magazine. This network has also established a

web page that receives over 200,000 “hits” a year. Although not modeled after a Parent-to-parent program, specifically the one to one match, it is a mechanism for fathers with children with disabilities to connect.

National Parent-to-parent Support and Information Systems, Inc., NPPSIS

NPPSIS is a national resource for providing emotional and informational support to parents who have a child with special needs. This organization was established through the collaborative efforts of the National Parent-to-parent Coalition. Partial funding is received through the U.S. Department of Health and Human Resources, Maternal and Child Health Bureau.

NPPSIS provides one to one national and international parent matches. They have developed a database software program called “Special” that maintains a list of veteran parents from all states and many countries. This software is marketed by NPPSIS for sale to other Parent-to-parent programs. Accessibility is provided through a national toll-free telephone number, e-mail address, and a web page.

### Research Studies

#### Parent-to-parent National Survey

In the fall of 1988, the Beach Center on Families and Disabilities at the University of Kansas initiated a national study of Parent-to-parent programs.<sup>19</sup> Rationale for this study centered on the lack of information concerning the number and scope of the existing programs. From 1989 to 1992, 374 programs returned surveys; 263 of those programs replicated the original Pilot Parent model. These 263 programs assisted the Beach Center in sending out surveys

to the referred and veteran parents. A total of 240 referred parents and 331 veteran parents responded. Descriptive data analysis was utilized to provide information about program development and service availability.

#### Administrative Characteristics

The average size parent-to-parent program was providing support to between 13 and 25 referred parents.<sup>19</sup> Fifty-five percent of the programs indicated an annual budget of less than \$5000. Sponsoring agencies were the most common funding source with 46% of the programs receiving this type of financial support. Only slightly more than half of the Parent-to-parent programs had either a part-time or full-time paid coordinator, and a total of 78% of the coordinators responding were parents of a child with a disability. Referred parents indicated that 85% had a child with special needs who is younger than 12 years of age.

#### Referrals

Referrals into the Parent-to-parent programs came from a variety of sources; 29% reported that a doctor or nurse referred them and 19% indicated that a social worker connected them to the program.<sup>19</sup> Other referral sources mentioned included Parent-to-parent representatives at 13% and a teacher or parent each at 7%. The time reported from the initial call to the program and the new parents receiving their first contact was within one week of the referral for 68% of the new parents. Matches were based on a number of different factors; the majority, 76%, reported that their match was based on similar disability issues and 55% indicated that similar family issues were a factor in their match.

Similar age, within two years, was mentioned by 25% of the parents. Other factors mentioned were similar family structures, parents were about the same age, geographic location, and the availability of the veteran parent to respond within twenty-four hours. These contacts can be brief or result in a lifelong friendship. Referred parents responding to the survey said that 50% of the matches had lasted more than one year and 56% had at least seven contacts.

#### Types of Support

Matched parents received a variety of emotional and informational supports.<sup>19</sup> Opportunity for someone to listen and understand is considered the prime function of a Parent-to-Parent program. In this national survey, 100% of those who responded indicated that they matched parents for support. Information about the disability was available from 98% of the programs. Other supports offered were information about community resources occurring in 50% of the programs surveyed, with referral to other agencies and training also being mentioned.

#### Training

The amount of training for veteran parents varied, but 76% reported that they did provide initial training before matching.<sup>19</sup> Veteran parents in 44% of the programs received 10 hours or more of training. Topics for training ranged from listening skills, adjustment to the diagnosis, orientation to goals, activities and philosophy of Parent-to-Parent.

## Demographics and Type of Disability

The greatest percentage of parents responding to the survey was Caucasian, at 88%.<sup>19</sup> Two-parent households accounted for 90% of the respondents with 35% reporting an annual income over \$50,000.

Parents utilizing the support network had children with a wide range of disabilities. Developmental Delays (31%), Down syndrome (29%), and mental retardation (23%) were mentioned most often.<sup>19</sup> Parents indicated that the severity of the disability was moderate or severe in 64% of the cases.

## Review of Statewide Parent-to-parent Digest 1998

The Beach Center produces an updated statewide Parent-to-parent Digest every other year prior to the International Parent-to-parent Conference.<sup>20</sup> Each program is free to submit information regarding their operation and organization. The 1998 digest included information from 20 different states.

## Administrative Characteristics

In contrast to the 1989-1992 Beach Center study, the 1998 Statewide Parent-to-parent Digest listed an average annual budget in 1998 at \$316,557 (nine programs reported) as compared to \$5000 previously.<sup>20</sup> Additionally, the trend has changed from the earlier study of only slightly more than half having either one part-time or full-time employee to the 1998 average of 12 part-time or full-time employees (14 programs reported).

## Funding Sources

Another change is in relation to the most common funding source.<sup>20</sup> The earlier study indicated that sponsoring agencies were the most common at 46%;



whereas in the 1998 digest, with eleven programs reporting, state or federal dollars funded 72%.<sup>20</sup> State Developmental Disabilities Units, Maternal and Child Health Agencies, and the Department of Education were most often cited as the sources of state funding. Unique funding sources for some programs were Native American Tribal monies and the Episcopal Diocese. One program was funded 100% by a hospital.

### Training

According to the 1998 Statewide Digest,<sup>20</sup> 100% of the programs are providing parent training as compared to 76% in the 1989-1992 Beach Center National Study. The length of training in 1998 varied from two hours to two days. It is important to note that the mechanism for training is changing to include mail out packets and videotapes. Two programs indicated a need to reduce the time required for training and offer a personal and telephone interview to bring parents "on board" who they feel do not need a lot of training. The rationale supporting this method was the realization that a lot of parents have had opportunities outside of Parent-to-parent networks to learn how to be good listeners or learn coping skills and strategies.

### Collaboration

Perhaps the growth of budget and employee base can be partially contributed to the outreach and collaboration reported by many of the programs in the 1998 digest.<sup>20</sup> Cited most often was a tie-in with the medical and special education professionals. Training students at university medical schools was reported by 7 of the 20 programs. Parent Training and Information Centers (PTI)

collaborated with three of the Parent-to-parent programs.

### Beyond the Match

Some unique features provided by programs included such services as provisions of a central directory for Early Intervention programs throughout the state and provisions of a lending library.<sup>20</sup> Further outreach has been done in the area of connecting adoptive parents of children with special needs, conducting minority outreach workshops entitled, "Talk to the Doctor," and dedicating a staff member to assist families with Social Security Income (SSI), managed care, and Medicaid.<sup>20</sup>

### Parent-to-parent National Efficacy Study

During the 1992 International Parent-to-parent Conference, a small group of parents and researchers met to discuss the need for quantitative data on the effectiveness of the one to one Parent-to-parent match.<sup>21</sup> These parents questioned if data were available that validated what parents had been saying informally about the value of Parent-to-parent support. These data would be useful in convincing potential funding sources and referral sources about the importance of one to one Parent-to-parent support. The group expanded to include parent leaders from five states in three regions of the country: the Midwest, New England, and the Southeast. A group of researchers from universities located in or near these five states convened with the parent leaders in the summer of 1992. Most of the researchers had previously conducted family based research and many had personal experience with disabilities in their families or life.

In order to define the research questions, the group reviewed the goals and objectives of Parent-to-parent programs and their perceived outcomes.<sup>21</sup>

Based on this discussion, the group identified three goals as follows:

- To increase the informational support that is available to parents who have a child with special needs.
- To increase the emotional support that is available to parents who have a child with special needs.
- To provide this emotional and informational support by offering parents a one to one match with a veteran parent.

Using the definitions of the program goals and objectives, this group identified seven different evaluative questions to answer, three outcome questions, and four process questions.

The outcome questions were:

- What is the impact of the one to one match on referred parents' (a) sense of having a reliable ally, (b) sense of empowerment, (c) sense of social support, (d) sense of being able to cope, and (e) acceptance of the disability issues?
- How do parents rate the value of Parent-to-parent?
- What is the impact of the one to one match on referred parents' progress in meeting their need they first brought to the program when asked for assistance?

The process questions were:

- How does the number of contacts with the supporting parent affect the referred parents' satisfaction with Parent-to-parent?
- How does the age of the child and number of years that the parent has known about the diagnosis affect the impact of the one to one match on referred parents?
- According to consumers of Parent-to-parent supports, what makes the programs effective?
- When Parent-to-parent does not help parents, what are the reasons?

The study involved a two-group experimental design with quantitative measures and a qualitative interview. The team of parents and researchers in each of the five states recruited parents who had a child with a disability and who had never been in a Parent-to-parent match. Parents, through random selection, were assigned to either an experimental group that received a Parent-to-parent match or a control group that did not. Follow-up was for one year with each group completing questionnaires several different times over the course of the year. Based upon the parents' response on the questionnaires about the helpfulness of Parent-to-parent, they were separated into two groups, one who found it helpful and one group that did not. Interviews were then conducted to learn about the parents' experiences.

A dilemma arose in that the parents involved in the research believed that it was unethical to deny parents in the control group immediate Parent-to-parent support for the sake of research.<sup>21</sup> Without a research design that was family

sensitive, the research group felt they would not have the backing of parents and Parent-to-parent programs. However, without a well-respected research design, they were concerned that the results would not be viewed as credible by other researchers and potential funding or referral sources for Parent-to-parent. A compromise was reached in that the control group would only have to wait eight weeks until they were matched. Additionally, no parent who wanted to be matched right away would be denied that opportunity.

Parents on the research team suggested that a typical match should involve at least four contacts over an eight-week period.<sup>21</sup> Thus, the research design required a minimum of four contacts during the first eight weeks of the match.

Instrumentation tools selected for the research were:

- Kansas Inventory of Parental Perceptions, a measure of positive attitudes about a child with disability in the family
- The Family Empowerment Scale, used to assess perceived changes in parent's sense of being empowered
- Social Provisions Scale, a measure of perceived social support and its function

Additionally, two other measures were developed for this study:

- Parent Coping Efficacy Scale, a measure of parents' self-efficacy in dealing with challenges posed by their family and child with a disability
- Questionnaire asking parents how helpful Parent-to-parent was

Parents in both groups were asked to complete a total of four

questionnaires during the course of the one-year study.<sup>21</sup> The timing of the questionnaires was set 1) before randomization, as a pre-test, 2) at three weeks after randomization, 3) at two months after randomization, and 4) at six months after being matched. Additionally, 24 parents, 12 who had reported that Parent-to-parent was helpful and 12 who did not share that same perspective were interviewed by telephone using a standardized protocol.

A total of 128 parents participated in the study, 72 in the control group and 56 in the treatment group.<sup>21</sup> ANCOVA was used to control for any group differences at pre-testing. Not included in this sample were a total of 28 parents who indicated that they had an urgent need for assistance.

Subscale for the Kansas Inventory of Parental Perceptions was derived from a factor analysis based upon a sample of 1262 parents of children with disabilities.<sup>21</sup> Responses to the seven questions were scored on a four-point scale with “strongly disagree” scored as 1 and “strongly agree” as a 4. The findings suggested that participation in Parent-to-parent had a significant influence on attitudes that are thought to be crucial to parental adaptation to the disability. ( $F(1,127) = 16.62, p = .000$ .)

The Family Empowerment Scale consisted of three subscales designed to measure perceived empowerment in three domains: Family, Service System, and Community/Political.<sup>21</sup> Answers were structured on a five-point scale ranging from “not true at all” scored as 1, to “very true” scored as 5. Internal consistency used the computation of alpha coefficients found to be in the range of .87 to .88 for the three subscales. The findings suggest that initial contact with

Parent-to-parent does not change the perception of empowerment. ( $F(1,125) = 2.42, p = .122$ .)

Subscales of coping with child and coping with family were used to measure efficacy in the Parent Coping Efficacy Scale.<sup>21</sup> This instrumentation was developed for this study. Respondents answered 24 questions that were then assigned a rank on a five-point scale with “not capable” scoring 1 and “very capable” scored at 5. Internal consistency coefficients were calculated with  $\alpha = .89$  for the family subscale and  $.88$  for the child. Test-retest reliability was  $r = .82$ . Findings indicated that there was significant difference between the groups of parents who entered the study with perceived coping skills below the 3.07 level. Parents, from either group, who scored above the 3.07 levels on the pre-test showed no significant difference.

Referred parents were asked to answer two questions to measure whether progress had been made on the specific problem about which they initially contacted the Parent-to-parent program.<sup>21</sup> Questions were: “What is the major specific need that is influencing you to seek Parent-to-parent support?” Secondly, “How much progress have you made in getting that need met?” Answers were scored on a four-point scale with “none” scored as 1 and “a lot” scored as 4. ANCOVA revealed significant difference between groups at the post-test when pre-test scores were used as a covariant. ( $F(1,125) = 13.79, p = .000$ .) This suggests that matched parents made significant greater progress in addressing the problems that initially brought them to the Parent-to-parent program.

Parents receiving matches upon entering the study were asked about the number of contacts with the veteran parent.<sup>21</sup> A majority of the parents, 61%, had one to two contacts, 28% reported three to four contacts, 8% had five to six, and the remaining 3% had ten or more.

Qualitative analysis was utilized for the interview portion of the study.<sup>21</sup> Of the 12 parents in the treatment group, 89% rated the program as helpful, 11% as not helpful. Interviews were transcribed from audio tape recorders and subsequently similar themes emerged from all 24 interviews. This thematic analysis suggested the Parent-to-parent program was effective in reducing the parents' sense of isolation. Parents who did not find the Parent-to-parent program helpful either had a problem that made contact difficult or they did not feel a perceived sameness with the veteran parent. Specifically, one parent with a child with cerebral palsy who was nonvocal was matched with a parent of a child with cerebral palsy who spoke.

Principle findings of this research indicated that Parent-to-parent program support increases parents' sense of empowerment, acceptance of their situation, their ability to cope, and progress on the initial problem confronting the referred parent once they had been matched.<sup>21</sup> A correlation existed between the number of contacts between the referred and veteran parents and the perceived level of helpfulness.

Outcomes from this study have resulted in new procedures for program coordinators involved in the research.<sup>21</sup> One change addressed the need to monitor matches and respond quickly if they are not working or do not lead to



more than one phone call. Since respondents indicated that an increased number of contacts directly related to the perceived level of helpfulness, directors actively aim to increase contact between matched parents to at least four during the first eight weeks.<sup>22</sup>

#### Future Directions

According to Kagan and Weisbourd,<sup>23</sup> regardless of new funding possibilities, the role of family support programs as partners with other service providers and community resources will continue. These authors suggested that, for each community, family support be defined more by its approach and its responsiveness than by its specific service. Furthermore, families and service providers need to work together to facilitate and advocate for support needed by families. Additionally, funding should continue to come from a variety of sources and, by this act of commitment to families, this partnership should focus on building the capacity of families to identify and fully utilize all the resources available to them.

As reported by Singer and Powers,<sup>24</sup> some creative arenas into which programs have expanded include: 1) computerized database available to healthcare providers, 2) matching of parents prenatally, 3) providing services to families for whom English is a second language, 4) reaching out to teenage parents, and 5) providing “one-stop” shopping for families with services addressing financial, legal, transportation, respite, medical, and educational needs.

Despite all of these exciting developments, the mainstay of Parent-to-parent programs continues to be the one to one relationships.<sup>5</sup>

## CHAPTER III

### METHOD

This project was funded by Federal Part H funding through a grant from the Developmental Disabilities Division of the North Dakota Department of Human Services. The project was designed to complete research that would determine the feasibility and need of a family-to-family network within the state of North Dakota.

#### Objectives

This research project was to include instrumentation to determine (a) the priorities of families regarding a family-to-family network and be responsive to needs of families in the rural environment; (b) identify programs and agencies currently providing family support services within the state and promote interagency collaboration; and (c) identify potential funding sources.

Objectives (a) and (b) above will be addressed as the initial focus of the research basis of this project. Objective (c) will not be reported in this study.

On May 28, 1997, the initial planning committee met at the University of North Dakota, Department of Physical Therapy. This committee consisted of the following people: Peg Mohr, Linda Olson, Deanne Horne, Keith Gustafson, Tammy Stuart, and Laurie Lacrosse-Bruggeman. At that meeting, it was determined that an advisory board, comprised of parents of children with a

disability and providers, be created to assist in the planning process. Tammy Stuart organized the members of this board and served as chairperson. Members included Tammy Stuart, Kari Chaissen, Rick Blair, Donene Feist, and Ron and Becky Lawler. Based on the recommendations of the planning committee and advisory board, two different survey instruments were developed; one addressed the agencies and providers, while the other addressed families with children with disabilities. Both the Agencies/Providers and Families with Children with Disabilities were addressed independently.

#### Subject Selection for the Research of Agencies and Providers

This portion of the study focused on agencies and providers that had contact with families with children with disabilities between the ages of birth to 21. A mailing list for the survey was created by identifying agencies/providers through the following contacts: (a) University of North Dakota School of Medicine and Health Sciences (UNDSMHS) provided a current listing of family practitioners, general practitioners, and physicians who specialize in pediatrics and orthopedics. (b) Mary Ebertowski, Department of Pediatrics, UNDSMHS, provided a listing of clinical sites, school districts, and a variety of support groups. (c) Deanne Horne provided the 1996 database listing from the North Dakota Services Directory for Persons with Developmental Disabilities. From these lists, a sample group of 1000 was selected.

Permission to collect data from these agencies/providers was granted by the University of North Dakota Institutional Review Board (IRB). (See Appendix

A.) The completion and return of each individual questionnaire indicated voluntary participation.

#### Instrumentation for Agencies and Providers

Betsy Santelli of the Beach Center on Families and Disability, University of Kansas, provided a model of the Parent-to-parent National Survey for program administrators. This model was used to guide the design and planning for the survey.

On June 13, 1997, the planning and advisory committees met and reviewed sample agency surveys with an emphasis on correlating the survey with the Family Involvement Subcommittee's initial goals for this project. Those five goals presented to the North Dakota Interagency Coordinating Council in July of 1996 were as follows: 1) offer a first response program for families of children with disabilities utilizing parents trained in first response techniques, 2) provide family-to-family network awareness activities for families of children with disabilities and service providers, 3) collaborate with existing groups that provide support to families who have children with disabilities, 4) create a family database in order to act as a clearinghouse to match families, and 5) create a computer network sensitive to family needs.<sup>25</sup> Survey question content and clarity were critiqued. Based upon suggestions of the planning and advisory committees, questions were added, deleted, or rewritten.

On June 13, 1997, a presentation was made to the Family Involvement Subcommittee to obtain additional feedback on the survey design and content. The final draft was submitted to the Bureau of Educational Research Services.

Support staff from the Bureau reformatted the survey to fit on a two-sided postage paid mailer. (See Appendix B.)

#### Procedure for Agencies and Providers

On August 1, 1997, surveys were mailed to the 1000 subjects previously identified. Included with the survey was a cover letter (see Appendix C) explaining the research project and inviting them to participate. The cover letter also assured confidentiality of responses and gave a preliminary thank you for the response. Additionally, the cover letter asked for completion and return of the survey by September 30, 1997, with an approximate completion time of ten minutes. On August 27, 1997, a postcard reminder was mailed to serve as an encouragement to complete and return the survey. A second cover letter and survey were mailed to nonresponders on September 10, 1997. The closing date for return of the surveys was September 30, 1997.

#### Data Analysis for Agencies and Providers

Data from the returned surveys were entered into the computer for statistical analysis by staff from the Bureau of Educational Services and Applied Research at UND. The researcher elected not to interpret results when the probability exceeded .05. Statistical data were compiled via the Statistical Package for Social Sciences (SPSS-Macintosh Version 6.1) (SPSS Inc., 1994). Descriptive statistics identified relationships in demographics, job title of the responder, current levels of family support, and perceived need for a statewide family-to-family network. Comments to open-ended questions were organized and categorized according to major and minor themes. Cross tabulations were

done to investigate any correlation between job title of the responder and perceptions as to need for a family-to-family network and current family support activities of their agency.

#### Subjects for the Research of Families with Children with Disabilities

In a conference call on May 29, 1997, between Peg Mohr, Deanne Horne, Laurie Betting, and Keith Gustafson, the feasibility of doing a parent sampling during July of 1997 was discussed. Keith suggested, rather than follow the traditional survey method, holding focus interview sessions across the state with families with children with disabilities.

During the June 13, 1997, planning and advisory committee meeting, a decision was made to utilize the focus group concept. Each focus group would have a parent coordinator, interviewer, and recorder. It was also determined that seven sites would be set up across the state between August 4 and 14, 1997, each to include up to ten families.

Members of the planning and advisory committee who are themselves parents of children with disabilities volunteered to be parent coordinators and contact other parents of children with disabilities for the interview process. Again, Keith Gustafson provided an example of a working outline based on Richard Krueger's text for the parent coordinators that was adapted for this project. (See Appendix D.) The families invited were to represent a variety of disabilities, length of time since diagnosis, age of the child with the disability, and come from varied population bases.

Once the committee members secured families for these sessions, the names and addresses were forwarded to Peg Mohr for mailing of a parent notification letter. (See Appendix E.) This letter explained the interview process and also assured confidentiality of responses. Attending the Focused Interview Session indicated voluntary participation by the families.

With the signed cooperating institutional consent forms in place, approval for this research method was sought and obtained from the Institutional Review Board (IRB) at the University of North Dakota (UND) (see Appendix F).

#### Instrumentation for the Families with Children with Disabilities

During the initial contact from the Parent Coordinator, parents were informed that the focused interview session would last approximately two hours. The notification letter informed them that they would have the opportunity to discuss experiences and issues within their families that have influenced their ability to cope with having a disability affect a child. In addition, parents were told they would be asked to address issues and concerns they have regarding access to community and social supports, the influence of rural environments, and the essential components of a family-to-family support network. It was the intent of the researcher to make families feel comfortable and allow interchange between families. Due to these parameters, the questions for the actual interview were kept at a total of nine to allow adequate time for sharing (see Appendix G). The Family Involvement Subcommittee selected the final questions, although this researcher suggested alternative questions. (See Appendix H.) Questions 1 and 2 were aimed at putting the families at ease and



promoting mutual areas of identification. Question 3 asked families to share a difficulty or barrier relevant to their home or community that existed because of their child's disability and what they did to resolve the situation, while question number 4 asked them to name the greatest challenge in being the parent of a child with a disability. Questions 5 and 6 were aimed at identifying formal or informal support for their family. Finally, the remaining questions asked parents to envision what elements they would include in a system for helping other parents rear and educate their child with a disability and with whom they would be most like to dialogue.

At the conclusion of each session, families were to asked to either take a few minutes to complete a brief questionnaire or take it home to complete and mail in. These questions sought input regarding training programs for veteran parents and effective methods of recruiting veteran parents (see Appendix I). A separate page was attached asking if parents were willing to serve as veteran parents, and an envelope was provided to preserve confidentiality of their responses to the prior three questions (see Appendix J).

#### Procedure for Families with Children with Disabilities

Keith Gustafson provided a working outline based on Krueger's text that was adapted for both the interviewer and the recorder (see Appendices K and L).

It was the responsibility of the interviewer to collaborate with the parent coordinator and recorder to select the time and date for the focus group. Arrangements for the room and refreshments were also the responsibility of the interviewer. It was recommended that the group not meet at a school due to

possible adverse relationships between families and the educational realm. Each session was to be tape-recorded and the tapes forwarded to Peg Mohr for transcription as well as to protect confidentiality. Name cards were provided for each participant as well as easel paper with each question printed separately on a sheet.

The recorder received training regarding completion of the Focus Interview Analysis Worksheet (see Appendix M). All nine questions were addressed separately with space to summarize the key points from each of the families participating in the process. Furthermore, the recorder was instructed to listen for and record notable quotes that might illustrate an important point of view. Prior to concluding the session, the recorder was asked whether or not he/she had anything to add or any questions/responses that required clarification. The recorder was charged with the responsibility of submitting the field notes and tapes to Peg Mohr within 24 hours of the session.

As each family arrived to the Focus Interview, both the parent coordinator and the interviewer greeted them. A suggested introduction text was provided for each of the interviewers (see Appendix N). It was stressed to the families involved that there were no right or wrong answers but rather differing points of view and different types of support that family members value. Ground rules were established for each session in regard to the sharing opportunities. Only one person was to speak at a time to provide clarity of the recording and allow others to hear the comments. The start of each new question rotated around the room in order to give all families the same opportunity to respond first, second,

and so on. Each session concluded with the interviewer expressing appreciation to the families for their willingness to participate and to take time out of their busy schedules. Additionally, at the conclusion, the interviewer asked parents to fill out a brief questionnaire regarding content areas of training for families, effective methods of recruiting veteran parents, and identification of those they felt might benefit from the availability of a family-to-family network other than the families themselves.

#### Data Analysis for Families with Children with Disabilities

Handwritten notes were provided for all seven of the focus interview groups. Due to technical difficulties, only five had taped the sessions and support staff for the research project transcribed these tapes. Only the five groups with transcribed notes will be reported in this study. Descriptive statistics were utilized for the nominal data. Questions 1 and 2 described both the time and nature of diagnosis for the child with a disability, the family size, and favorite pastimes for each particular family. Phenomenology data analysis was implemented with triangulation to report common themes and denominators. Additionally, memorable quotes from the family members were compiled. (See Appendix O.) Confidentiality was maintained for all aspects of the data analysis.

## CHAPTER IV

### RESULTS FOR THE RESEARCH OF AGENCIES AND PROVIDERS

Survey instruments were mailed to 1000 agencies/providers previously identified as providing services to children with disabilities ages birth to 21. Two hundred and twenty-five surveys were returned for a return rate of 22.5%. It was anticipated that a number of surveys were not returned due to seasonal demands of school start-up, physicians indicating no involvement with children with disabilities, and agencies not offering any type of family support. The Bureau of Educational Research Services, according to traditional descriptive and analytical statistical methods, tabulated results. Open-ended responses were categorized and analyzed for themes. Below, demographics of the respondents are reported first, followed by the survey results relative to each of the original research questions. See Appendix N for complete survey results.

#### Demographics of Agencies and Providers

Five percent of the respondents indicated that they were parents of a family member with a disability and 32% indicated that they were a practitioner in a disability field. Fifteen percent reported they were a paid office-support staff member, while only 1% indicated they were a volunteer within their program or agency. The remaining 47% selected "other" as their response.

After review of the initial findings, it was decided to further explore the category of "other." The personnel at the Bureau of Educational Research Services suggested that two new categories be created: one to be recoded as practitioners in a non-disability field and one for administrators. The category of practitioners included physicians, nurses, and social workers. Rationale for separating the practitioners from administrators was based on the assumption that likely their perspective in many of the survey items may be different. The previously reported "other" category now became 28% practitioners in a non-disability field, 16% administrators; the remaining 3% could not be identified, so remained as other. This breakdown of respondents was utilized to run cross tabulations on six of the survey questions.

Agencies and providers were asked to provide a mission or purpose statement. From those statements, 12% were identified as having family support services as part of their mission statement.

Survey question number 8 requested that the respondent describe the type of community in which their agency or program operates. Twenty-eight percent of respondents indicated that the community from which they operate is a city with population between 25,000 and 100,000. A town with population between 2,500 and 25,000 was selected by 19%, while 13% selected small town of 2,500 or less population. Five respondents indicated that their agency or program operated in a rural locale but not farm, for a total of 2%, and only one selected farm as their operating site which amounted to less than one percent. Although no space was allowed for write in answers, a total of 38 respondents

indicated something other than the five categories provided. Eight percent reported that they provided services for one or more counties and 10% indicated statewide service. Eight percent of those selected multiple categories and wrote in an explanation as to multiple sites or areas of operation.

Since the advisory board was concerned about how to handle confidentiality, this topic was incorporated into the survey. Question number 24 was open ended and asked, “How do you address the issues of confidentiality”? Forty-six percent of the respondents provided information on confidentiality. Over 98% cited Federal Family Privacy Act (FERPA) or Individuals with Disabilities Education Act (IDEA) as the standard for confidentiality in their program or agency. The remaining 2% did not have a policy or guideline in place as of that date.

**Research Question 1: What are the priorities regarding the need for a family-to-family network: effective mechanism for implementation?**

**Survey question 9**

*Please indicate your referral source. (Check all that apply.)*

The information obtained from this question would identify mechanisms currently being utilized by families with children with disabilities. A total of eight sources were listed with the number 8 indicating “other” accompanied by a request for specification.

Figure 1 provides a cross tabulation for this survey question with the position held by the respondent within their agency. Neither category of

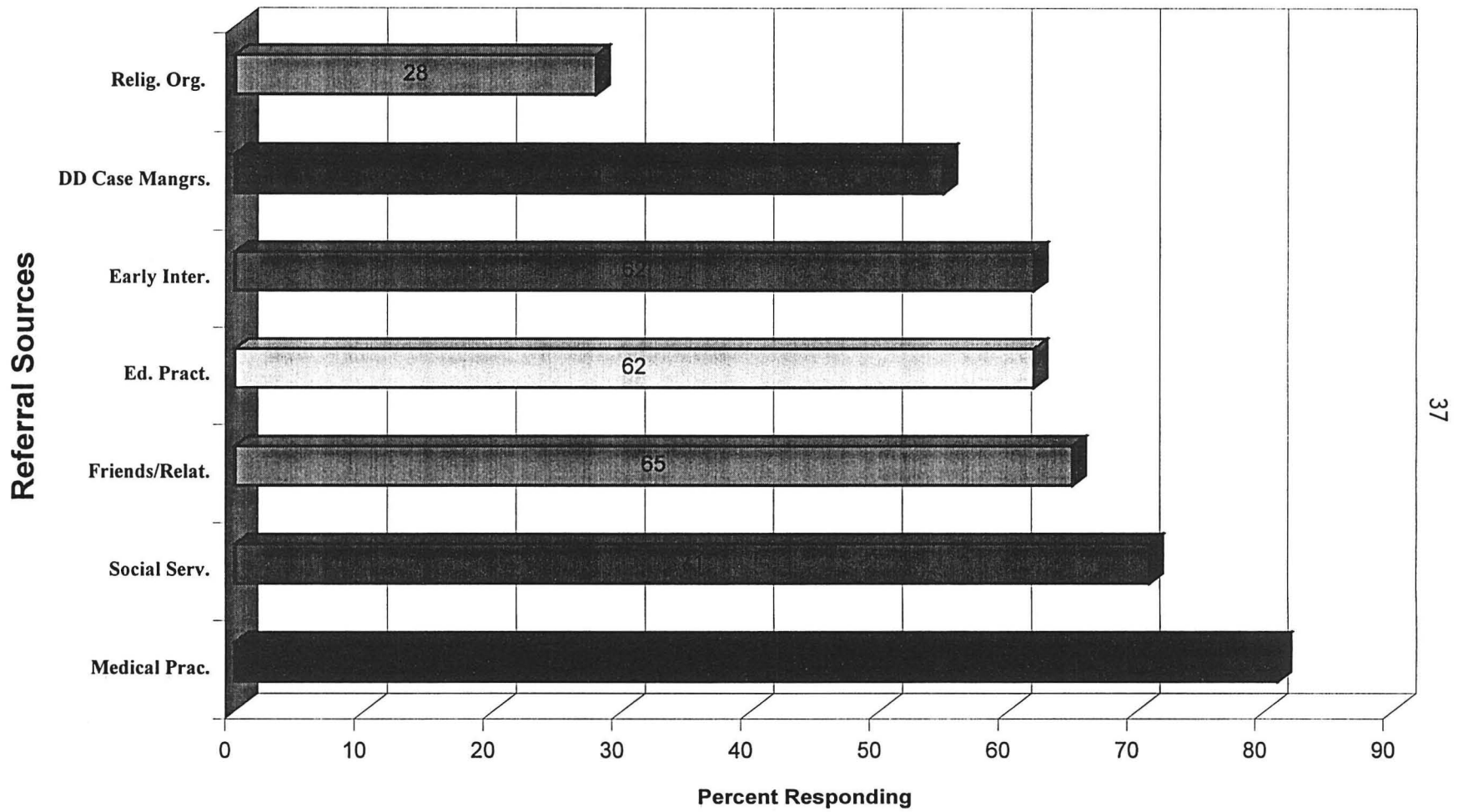


Figure 1.—Referral Sources

“Volunteer” nor “Other” was in this survey question. Of the five groups of respondents, three groups indicated the number one referral source was “Medical Practitioners/Facilities” and of all respondents 81% selected this item. The second most common referral source was “Social Services Practitioners” at 71% followed by “Friends or Relatives” at 65%. Both “Educational Practitioners” and “Early Intervention Practitioners” were selected at a rate of 62%. “Developmental Disabilities Case Managers” were selected by 55% of the respondents and 28% indicated “Religious Organizations” as a referral source.

#### **Survey question 18**

This question asked for a yes or no response to the question, *“Would a statewide family-to-family network be beneficial for the state of North Dakota?”*

Figure 2 indicates cross tabulation with a description of the position held by the survey respondent. Overall, 98% of the respondents indicated a “yes” response. The negative responses came from a practitioner in a disability field and office support staff.

#### **Survey question 19**

*If so, how do you perceive a statewide family-to-family operating in North Dakota?*

This survey question asked the program or agency to describe how they perceived a statewide family-to-family program operating in North Dakota. Forty percent of the total respondents wrote in information for this question. The major themes that emerged were:



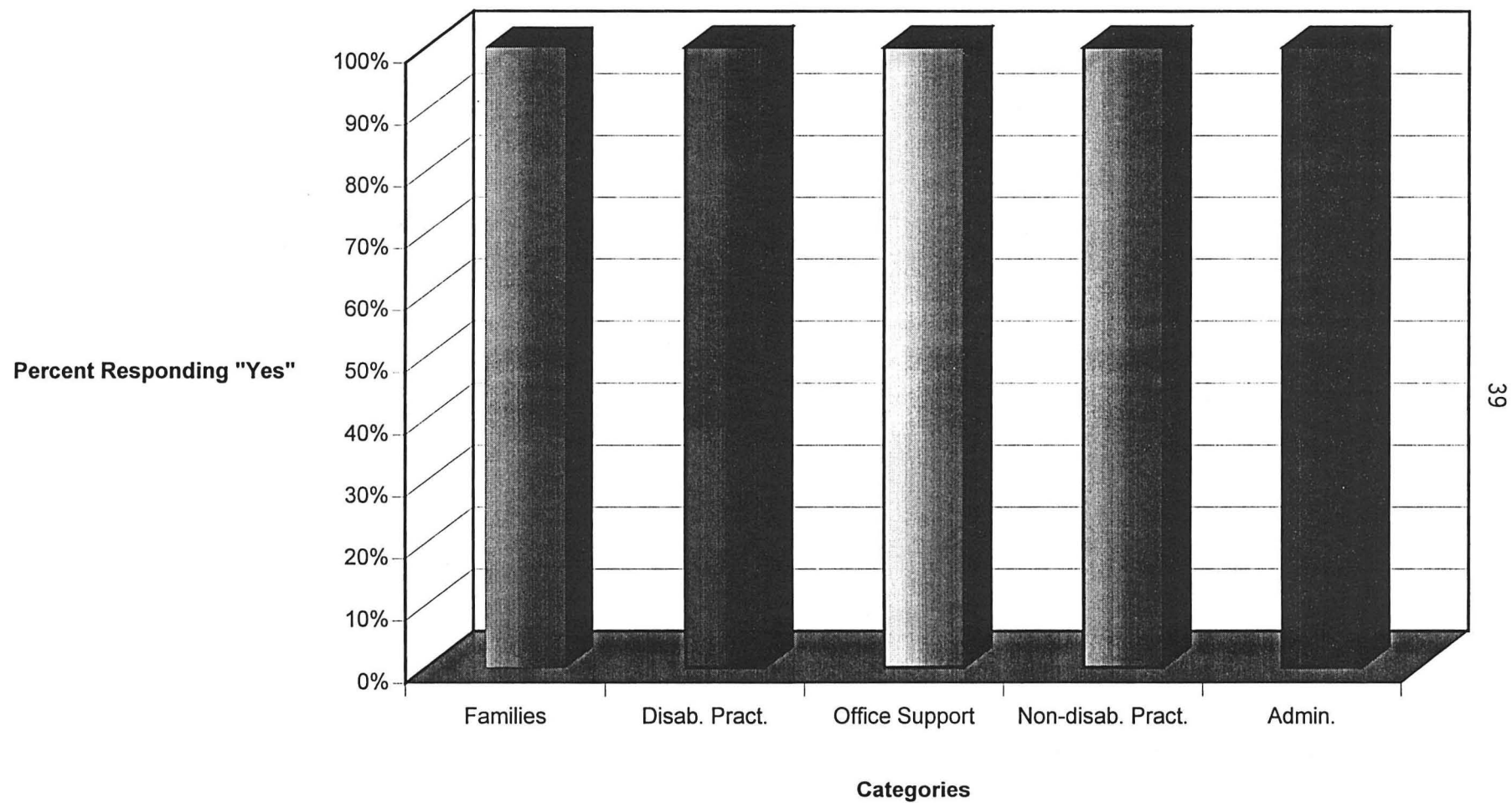


Figure 2.—"Would Statewide Family-to-Family Network be Beneficial for North Dakota?"

- 1) Cooperation or conglomeration of existing agencies
- 2) Freestanding database to be used by individuals or agencies
- 3) New agency required
- 4) Parent run agency
- 5) Regional agency rather than state level agency.

Figure 3 illustrates cross tabulation with a description of the position held by the survey respondent. Practitioners in a disability field and administrators both selected cooperation or conglomeration with existing agencies as their number response at 22% and 25%, respectively. Parents answering the agency/program survey indicated "Regional agencies rather than state level agencies" as their number one response; whereas, office support staff and practitioners in a non-disability field both selected a "freestanding database" as their most important component. Ten percent indicated the need for a 1-800 number or state phone line as the point of entry.

### **Survey question 20**

*What do you see as essential elements for a statewide family-to-family network? (Check all that apply.)*

A total of 12 items were available. Number 12 was "other" and asked for specification.

Figure 4 presents the results of the cross tabulations procedures. The number one essential element, at 75%, was "access at the point of need or diagnosis" followed by "orientation about the program" at 73%. "Training for participating families in communication and listening skills" was third at 64%

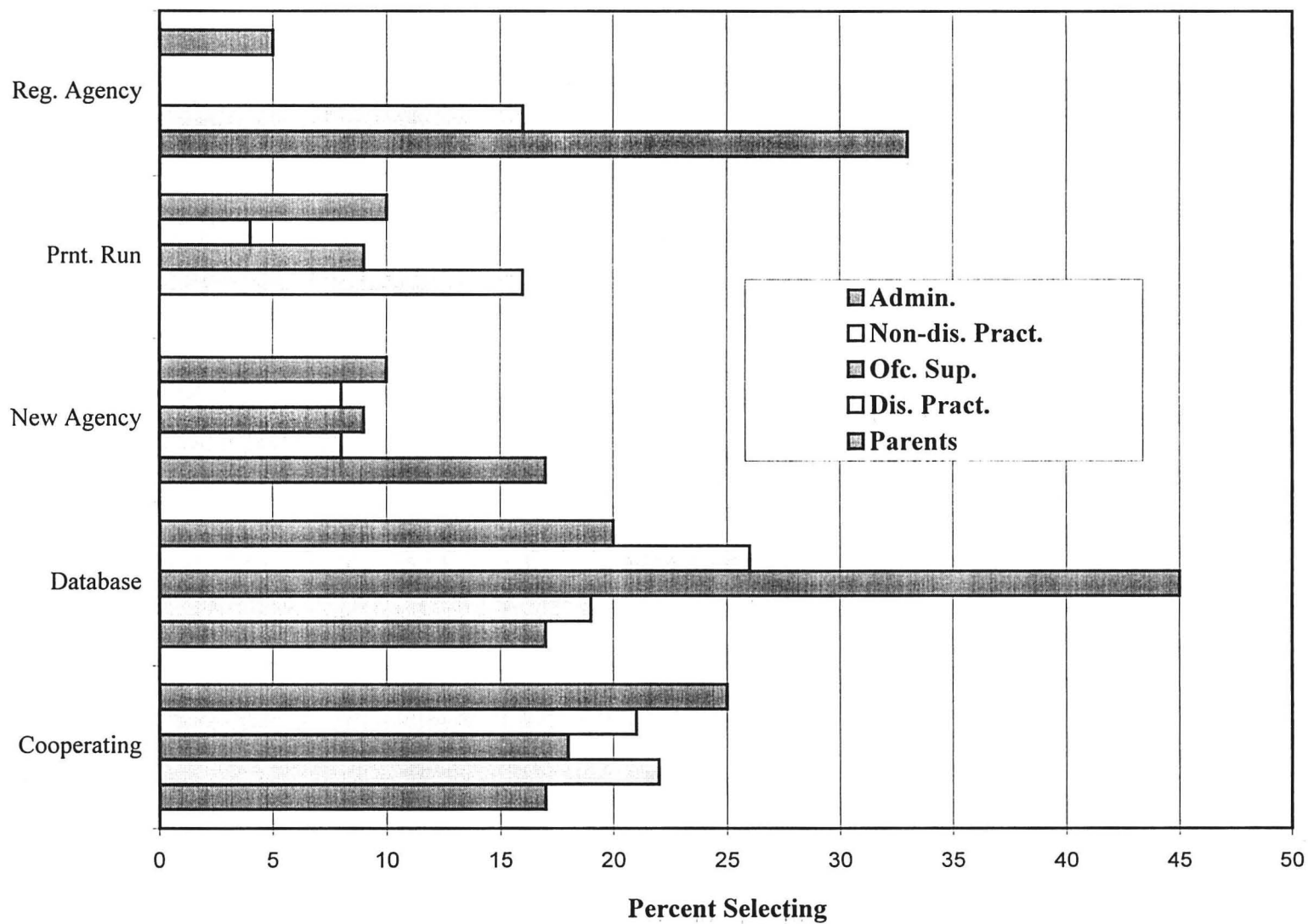


Figure 3.—"How Do You Perceive a Statewide Family-to-Family Program Operating in North Dakota?"

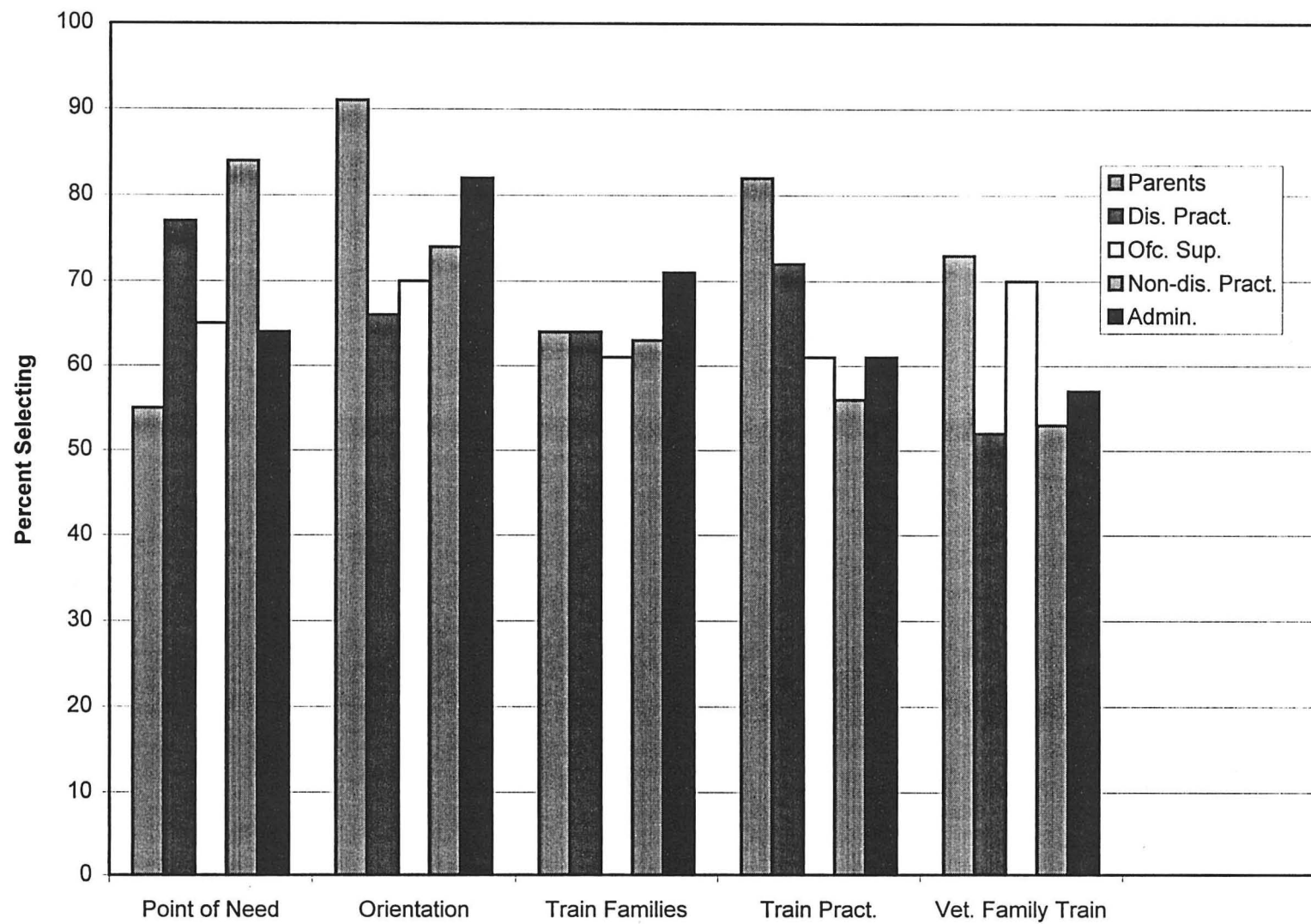


Figure 4.--Essential Elements for Statewide Family-to-Family

followed closely by “training to teach current practitioners and students preparing to work with families” at 63%.

Both practitioners in a disability field and those not in a disability field chose “access at the point of need or diagnosis” as the most important essential element. The first choice for parents, office support staff, and administrators was “orientation about the program.”

**Research Question 2: What programs/agencies currently provide family-to-family networking?**

A total of seven survey questions provided information related to this research question.

**Survey question 11**

*Do you presently match “new” parents/families with “veteran” or “supporting” parents for support?*

Only positive or negative responses were solicited. Overall, 28% indicated that they did provide some type of parent “matching” and the remaining 72% said that they did not. Of the 28% responding “yes,” 31% reported that the “matching” was done on an informal manner upon request.

**Survey question 12**

*On what basis are families matched? (Check all that apply)*

This survey question expanded on question number 11. Ten categories were provided and the tenth, which was “not applicable,” was selected by 53% of the respondents.

Table 1 gives the responses In order of descending frequency. The “other” responses included parent/teacher conferences, parent education classes, and similar technology needs.

Table 1.—Basis by Which Families are Matched

• 40.5% Families have family members with a similar disability
• 32.5% Families have faced same kinds of problems
• 21.6% Families have family member with disability about the same age
• 12.6% Families live relatively close together
• 8.1% Families have similar cultural or ethnic backgrounds
• 7.2% Families have about the same number of people in them
• 4.5% Other
• 3.6% Families have about the same educational level and income

### Survey question 13

*Please tell us how contacts between the “veteran” family and the referred family are usually made. (Check one)*

This question further explored the “matching” currently in existence across the state. Respondents were asked to report how contacts between the “veteran” family and referred family were usually made. Four options were listed: “by phone,” “in person,” “other” with an area for specification, or finally, “not applicable.” The most frequent response was “not applicable” at 58.3% followed by “phone contact” at 18.3%. “In person” was sited at 7% and the “other” category had a total of 16.5%. Responses to “other” included newsletters, letters, and family directories as a source of initial contact for families.

**Survey question 14**

*Currently, how many families are actively participating in family-to-family support activities?*

This open-ended question asked respondents to report how many families were actively participating in family-to-family support activities. The answers ranged from 0 to 500 with a total of 53 agencies or programs reporting. Six respondents indicated no known number.

**Survey question 15**

*Please tell us about the types of support provided to the families by families. (Check all that apply)*

The type of support provided to families by families was the theme of this question. A total of 11 categories were listed with the last one being “not applicable.” Respondents were instructed to check all that apply. Table 2 shows responses in order of descending frequency. Of the 9.2% who indicated the “other” category, 23% cited training or educational activities.

**Survey question 1**

*Do you provide training activities, initially or ongoing, for families?*

Only positive or negative responses were solicited. Cross tabulation again was performed. Responses were equally divided at 50% for both categories.

Table 2.—Types of Support Provided to Families

• 44.2% Not applicable
• 41.7% Someone to listen and understand
• 41.7% Information about the disability
• 40.8% Information about community services and resources
• 34.2% Information about living with/caring for a family member
• 32.5% Problem solving support
• 30.8% Referrals to other agencies
• 25.8% How to find best possible help for the family member
• 20.0% Group activities for support
• 18.3% Group activities for fun
• 9.2% Other

**Survey question 17**

*Please tell us about the content areas of training provided to families who would serve as “veteran” families. (Check all that apply.)*

This survey question was designed to identify the content areas of training provided to families who would serve as “veteran” families. Fourteen categories were listed with the last one being “not applicable.” The category of “other” asked for specification. Table 3 lists the training areas in order of decreasing frequency. In the category of “other,” the most frequently reported area was parenting skills.



Table 3.—Training Provided to Families

• 56.9% Not applicable
• 34.9% Information about community resources
• 26.6% Information about disability organizations
• 22.9% Planning transition
• 22.0% Orientation to the program
• 22.9% Listening and communication skills
• 19.3% Positive philosophy about persons with disabilities
• 17.4% Advocacy and legal issues
• 15.6% Self-awareness activities
• 13.8% Information about initial reaction to diagnosis
• 13.8% Information about financial issues/estate planning
• 7.3% Skills for working with culturally diverse families
• 7.3% Leadership training
• 7.3% Other

**Research Question 3: What opportunities for interagency collaboration and potential funding sources exist?**

A total of nine survey questions provided information to this research question. Topics addressed included collaboration issues, means and methods of communication, resources for inclusion in a network, ways a network could assist their organization, and the number of clients currently receiving services. Funding issues were also addressed.

**Survey question 3**

*Do you publish any newsletter or periodicals? If yes, please list titles.*

Respondents were asked if their agency or program published newsletters or periodicals and if so they were asked to list the titles. Sixty-three percent indicated that they did not publish any type of newsletter or periodical. Of the remaining 37% who responded positively, several reported a) that they published a newsletter and b) the frequency of publication.

**Survey question 4**

*Is information available in non-English languages? If yes, please specify.*

When asked if the information in their newsletter was available in non-English format, 19% reported “yes.” Thirty-five percent of those reporting “yes” said that Spanish was the non-English language in which their material was available. One respondent reported that they had the ability to provide material in eight different languages.

**Survey question 5**

*Is information available in non-print format?*

This question also addressed the range of formats for communication with clients. Specifically, it questioned whether the information was available in non-print format. Again, only positive and negative responses were solicited. Thirty-five percent reported a “yes” response, while the remaining 65% said “no.” Although no space was provided for a write-in response, nine agencies or programs added information to their positive responses. The information listed included videos, audio, and Braille.

**Survey question 6**

*Number of members or clients receiving services.*

Agencies/providers were asked to indicate how many members or clients were receiving services. Answers ranged from 0 to a nationwide range of 12 to 40 million served by the Social Security Administration.

**Survey question 7**

*Please indicate each of the following which apply; and if applicable, estimated annual cost.*

This survey question asked the agencies and programs to indicate if clients or patients paid dues or fees. Four categories were provided with a request to estimated annual costs. Four percent selected the category, "membership fees." Eleven percent reported either "fixed rate dues" or "fees," whereas 17% reported "variable fees or sliding rate." The most frequent response was "no charge" at 54%. Of the 13% that wrote in responses, three agencies indicated that they relied on donations, two said that funding was provided by a Tribal Nation.

**Survey question 10**

*Funding Sources: Please list the approximate percentage of funding that comes from each of the sources that apply.*

A total of seven options were listed, as was the category "other" with a request for specification. Table 4 lists funding sources in order of decreasing

frequency. The most frequent written-in response for the “other” category was insurance.

Table 4.—Funding Sources

• 49.0% Federal Grants
• 45.2% Local or State Grants
• 36.8% Fees
• 18.1% Sponsoring Agencies
• 11.6% Private Donations
• 11.0% Fundraising Activities
• 9.7% Other

#### Survey question 21

*What resources are available from your program that could be made available for inclusion in a resource library for dissemination to family-to-family programs? (Check all that apply)*

A total of seven items were listed. Additionally, the category “other” was provided with the request to specify. Table 5 lists responses in order of decreasing importance. Responses in the “Other” category included creation of a web site and books and pamphlets.

#### Survey question 22

*In what ways could a statewide family-to-family network be of assistance to your organization? (Check all that apply)*

Table 5.—Resources for Inclusion in Family Resource Library

• 72.6% Program Brochure
• 36.8% Newsletter
• 30.8% Information Packets for Referral Families
• 18.8% Database of Families
• 16.2% Slide/Video Show
• 16.2% Training Materials for Veteran Families
• 16.2% Other
• 6.0% Radio Spots

Table 2 provides cross tabulations. The number one response, 87%, from all groups was “serve as a referral resource to connect families.” Both “provide a mechanism to distribute information” and “referral source to service providers” were second at 60%.

### Survey question 23

*What additional resources might potentially be available to assist in the formation and/or support of a statewide family-to-family network? (Check all that apply.)*

Table 6 lists the eleven possible items, including the “other” category, which allowed room for specification. The items are listed in order of decreasing frequency. The “other” category included professional medical services and SDD program part H money.

Table 6.—Resources for Inclusion in a Family Network

• 66.9% Assistance with public awareness and referrals
• 45.8% Staff for consultation as resource persons and for training of parent volunteers
• 33.9% Office and/or meeting space
• 30.5% Speaker listing
• 19.5% A Family-to-Family Line for receiving referrals
• 19.5% A not-for-profit status of an established agency to qualify for funding
• 16.1% Assistance with fundraising and grant writing
• 12.7% Office equipment to maintain records and coordinate network
• 11.9% Underwriting of start-up and initial costs
• 7.6% Cash contributions
• 5.9% Other

#### Results for the Research of Families with Children with Disabilities

A total of seven focused interview group discussions were held between the dates of August 4, 1997, and August 14, 1997. These groups consisted of parents of children with disabilities, a facilitator, parent representative from the Family Involvement Sub-committee, and a recorder. The purpose of this design was to investigate the values and experiences of a small sample of families with children with disabilities relative to a) how they obtain support, b) what they would consider optimum design for a family-to-family network, and c) make comparisons between family groups, between families and agencies/providers and develop an initial conceptual framework that could be used to guide further studies. A total of nine questions were addressed during the interviews. See Appendix N for complete survey items.

A total of 23 written surveys were returned from parents at the conclusion of the focus interview sessions. The results from the three questions are reported in Appendix O.

#### Demographics and Eligibility of Families with Children with Disabilities

The seven sites were selected in an attempt to give representative input from both the rural and urban areas of North Dakota. Those sites were Bismarck, Bottineau, Fargo, Grafton, Grand Forks, Stanley, and Jamestown.

A total of 50 parents attended the interviews with 38 families represented by mothers only, 2 by fathers only, and 5 by both mothers and fathers. For Questions 2 through 9, only those focus interview groups that provided recorded tapes were transcribed and utilized for statistical purposes, including Grand Forks, Grafton, Fargo, Stanley, and Bottineau. Jamestown and Bismarck were not able to provide recorded tapes for transcription. For that reason, comparison will be made between the transcribed groups. Furthermore, for purposes of statistical analysis using qualitative research to address internal validity, a technique called triangulation was implemented. Triangulation refers to the use of multiple investigators with multiple sources of data for confirming or disconfirming emerging findings. For that reason, the five sites with transcription were further delineated by categorizing the site as either rural or urban. To qualify as urban, the population base for the location had to exceed 50,000; those under that number would be categorized as rural. Both Grand Forks and Fargo were placed in the urban category, whereas Grafton, Stanley, and Bottineau were all rural. Since one of the directives for the research was to “be

responsive to the needs of families in the rural environment,” the researcher needed to be able to discern whether or not differences existed between these groups. It is important to note that, although the focus group was held in either an urban or rural city, the families involved in the interviews were from the surrounding communities. Thus, a city qualifying as urban based on population size may well have had families with more of a rural outlook and experience.

#### **Interview question 1**

This question was designed to put the families at ease and allow them to begin to identify with other parents. Each participant was given the opportunity to share information about family size, children’s ages, where he/she attended school as well as family pastimes and hobbies.

The average family size was 2.7 children per family. Water recreation was the most frequently cited family activity, followed by sports and playing.

#### **Interview question 2**

This question sought information about the child with a disability. Parents were asked to share the time of diagnosis, nature of the disability, and how the condition influences the family both at home and in the community.

Parents reported diagnoses that ranged from before birth to as late as four years of age. Many parents did not report an actual time of diagnosis and stated that the process was ongoing and the diagnosis was evolving. The actual nature of the disabilities are categorized in Table 7.



Table 7.—Nature of Disabilities

• 9	ADD, ADHD, DD, or OCD
• 9	Multiple diagnosis
• 8	Cerebral Palsy
• 7	Down's Syndrome
• 3	Autism
• 2	Hearing/auditory processing

Single responses included Speech and Language Disorder, Short Term Memory Disorder, Sensory Modulation Disorder, Learning Disability, Spina Bifida, Visual Impairment, Arcadia Syndrome, Cornelia deLange Syndrome, Fetal Alcohol Syndrome, and Anoritter Wilms Syndrome.

When asked how their child's disability impacted family members at home, a few parents reported that their spouses, families, and extended families were accepting, supportive and dealing with the disability quite well. However, almost all of the focus group participants suggested that raising a child with a disability could be very challenging and, as one parent stated, "significantly life changing." Comments reported included "that raising a child with a disability is hard on our families and hard on our marriage." One parent stated that a parent's whole life and that everything done as a parent was centered around the child with a disability. Another parent suggested there was a lot of fear, frustration, worry, disappointment, sadness, and guilt associated with raising a child with a disability. One parent worried that more attention was paid to the child with a disability than was paid to the other children. This parent felt guilty

about neglecting the other children in the family. One parent offered, “you know how your other kids kind of grow up and you have an empty house for a few hours to catch your breath; you don’t really ever get those few hours to have some time alone.” One mother stated that there were problems with her spouse not accepting the child’s disability, while others expressed frustration with extended family members reacting in the same manner. Parents said some relatives ask inappropriate questions, lack education, and just generally do not understand their child’s behavior. There were also a number of sibling issues discussed which had both positive and negative impact on the family. Some parents felt that the siblings are more accepting of people with differences and have had to learn to be patient. Whereas, another parent suggested that her other children do not understand why she does not pay as much attention to them as she does to their sibling with a disability. A few parents stated how difficult it was for younger siblings to understand the nature of their sibling’s disability; for example, a sibling of a hearing impaired child not understanding why her brother cannot hear.

When asked how their child’s disability impacted family members in the community, a number of parents reported that their community has been very receptive, supportive, and understanding. One parent noted that her small town really “pulled together for the family in time of crisis.” However, the majority of the focus group participants noted that it is a “continuous battle” with lots of ups and downs and negative attitudes. One parent noted, “I have made my own community.” Parents noted the impact people’s attitudes and perceptions had

on their families. Parents of emotional disturbed children shared that “people expect a child to act normal because he looks normal,” and when the child misbehaves, people in the community are shocked and surprised. Another said that she notices that people in the community avoid them. A number of parents stated that it was very difficult, especially in small towns, to find a daycare that would handle children with disabilities. A few parents stated that their child’s inability to get out and about in the community hampered their child’s ability to integrate into the community. Wheelchair accessibility was a big issue facing these parents. They stated, “most things aren’t set up for wheelchairs” and that getting around in a wheelchair during the winter months was hard.

The impact of the school system on families was considerably significant. Many parents reported the schools were not supportive, that schools were frightened of their children, that schools have been resistant to working with their children, that teachers and counselors disagree or refuse to believe their child’s diagnosis, and that the schools are not interested in learning about their child’s disability. One parent stated that access was an issue, “just getting them into the building was the biggest challenge.” Another parent reported that “every transition has been difficult.” One parent stated that his child has been “kicked out of a number of schools”; another reported his child “gets kicked off the bus all of the time.”

**Research Question 1: What are the priorities regarding the need for a family-to-family network; effective mechanism for implementation?**

Focus interview questions numbers 3, 4, 7, 8, and 9 as well as written survey questions numbers 1 and 2 pertain to this research question. Both rural and urban themes were extrapolated.

### **Interview Question 3**

Parents were asked to think of a difficulty, barrier, or obstacle that they or their child had to face in regard to an issue relevant to their home life or community access. They were further asked to share what they did to resolve the crisis or situation. Three major themes arose from the urban (Grand Forks and Fargo) focus interviews. One dealt with difficulties with the education system and trying to locate daycare or respite care were their greatest obstacles.

Regarding the school system, one parent noted, "Getting services has been incredibly difficult." Another parent explained that they have to "fight to get our child into programs." A parent described that every year they have to re-educate teachers on their child's disability and are tired of telling their story over and over again. Another parent added that schools do not have appropriate planning, especially for extended school year programming, and that their children need structure and predictability year round.

Theme 2 centered on the isolation of being the child's only caregiver. One parent said that he/she was homebound. Two parents expressed their difficulty in doing the ordinary things that people take for granted, such as going shopping or being able to go out by themselves without worrying about who will take care of their child. Parents expressed the facts that not only were some of them socially isolated, but they were also isolated from information.

The third theme that arose from the urban cities centered on insurance issues. One mother told us that she was “constantly at the point of wondering what's in the mailbox; will we receive a big bill, will we be able to appeal it and when?” Another mother said that her husband farmed and she had to work at a job she did not like to provide insurance.

Two of the three major themes were repeated in the rural interviews; frustration with school systems and isolation or inability to “hook-up” with other families. Unique to the rural interviews was the lack of medical services or physicians. One mother said that her biggest concern was medical facilities and what they can handle with certain disabilities. Another mother said that her and her spouse were burnt out from being a doctor for their son when they just wanted to be parents. Finding a doctor who would believe the parents when they said something was wrong with their daughter resulted in them having to travel out of state.

A rural mother reported that there was a lack of Learning Disability staffing in rural areas as well as a lack of special educational/preschool programs. Around the isolation issue, two rural parents noted that access to childcare was especially difficult if you lived in a small town.

In many instances, the crisis or situation had no resolution. However, those parents who had found resolution stated they did so through educating people tactfully without being arrogant, phone calls to “higher ups,” threats, by taking a “hard line approach,” coming up with ideas for respite, and through seeking emotional support from church, community and family.

**Interview Question 4**

Focus group participants were next asked what they viewed as their greatest challenges in being a parent of a child with a disability.

The issue the urban and rural focus groups had in common was in the area of lack of sleep and enough time in the day to feel that they were good parents to the other children or a caring spouse. Urban and rural parents both noted the difficulty they had in achieving balance with other children in the family and just keeping the family together. Parents worried about the stress a child with a disability has on a marriage and relationship between a husband and wife. One father from a rural group stated that, in anticipation of upcoming medical challenges and needing to take time off, he keeps trying to save up a lot of sick leave and vacation at work. A mother from a rural group expressed frustration over the amount of instructions that health care providers gave her. She said she finally reached her limit and told a physical therapist, "Well, you take her home for a month and tell me how much you can get done. You work your job, you take my six-year-old, and you be the single parent and see how much you can get done." Parents from both rural and urban focus groups also noted they worried about the future and what will happen to their children when they are no longer around.

The educational system was again mentioned by rural participants as an arena that many parents feared. A few parents stated they were afraid to make waves for fear of being labeled a "trouble maker" or fear of retaliation on their child.

Financial and health care issues were also challenges reported by rural focus group participants. Parents worried about health insurance issues and not being able to afford equipment and therapies. A few urban parents reported their biggest challenge was in being well-informed. As one parent put it, “knowing and wanting what’s best for our child and getting physicians, teachers, and other professionals to help us obtain those things.”

### **Interview Question 7**

Focus groups were asked what types of supports and assistance they would build into their own system for helping other parents rear and educate their children with a disability. The most frequent response from both urban and rural groups was having other parents with children with disabilities with whom to talk. The second most frequent item, again with both groups, was having access to information and advocacy. A mother from an urban group stated that it would be ideal to all have access to the same information. She said that other parents of children with disabilities have come to her “trying to figure out what to do. They’re battling these everyday issues and then they’re on the phone battling other people . . . it’s hard to find the energy to do that and if you have one person who knows some of that information already because they’ve already been through it. If we were all together in one spot, it would make it a lot easier because you could say, hey, you know how to get that.” Although the groups both identified the same need, the perspective from the rural community was somewhat different. A mother explained, “The only thing that I can add . . . dream is that these rural towns could have the support and the accessibility as

all the big towns or just have somebody to reach out to. That it's difficult for us in the rural towns to get the help that the big ones do. And to have to bus your children to get the services they need and not to be in your home."

Availability of computers for parents to access the Internet for information on their child's disability was the third most frequently mentioned item by both that they would design into a system for families with children with disabilities. A family from an urban group spoke about their ability to access the Internet. "There's lots of things, there's lots of resources, you know, so you can find a lot of information and I can do that at nine o'clock, ten o'clock, on my time, when I want to do it."

The issue of training of medical professionals was discussed. Parents from both rural and urban focus groups felt that the medical community needed empathy training and education as to the need of parents. A rural parent shared that doctors "should go through some sort of sensitivity training and because they're constantly trying to tell me I don't know my child . . . I'm the enemy and they have no idea . . . you don't know what it's like until you're the parent and everybody else is looking around at you."

On a more personal level, parents suggested that having someone with whom to share stories and pictures would be an important component for a support system.

### **Interview Question 8**

When asked with whom these parents would like to dialogue in regard to a family-to-family network, the most frequently cited response, from both groups



by a two-to-one margin, was someone with a child with a similar disability. Having the same disability was second followed by “veteran” parents of any type, again from both rural and urban groups. Some parents mentioned that being able to dialogue with someone with an older child might be beneficial. Interesting to note is the fact that the 1991 National Parent-to-Parent study conducted by the Beach Center on Disabilities and Families asked the same question and received replies in the same order of importance.

### **Interview Question 9**

This question was used to wrap up the focus interview and ask these families to indicate the single most important support that was or would have been most valuable to these families. Both rural and urban focus group participants reported that “having someone to talk to who’s dealing with the same things you are” or being able to talk to other families as the number one support they would like to have. One family member described emotional and physical support as:

*I think I would sum it up in caring and that can be demonstrated by the emotional support that I need, the physical support, coming to repair a railing that’s falling down because you happen to know how to do that kind of thing. The caring that is a phone call out to the blue, just thinking about you today, how are you and your child doing. The caring that says, hey, I’m free this week, if you need a night off give me a call. The caring that*

*encompasses everything. It encompasses the support, being there for one another in tangible ways and in emotional supportive ways.*

The second most frequently mentioned item from both groups was having a mechanism to learn more information about the disability. Again, the findings of the National Study conducted by the Beach Center in 1991 was the same as the focus groups. "Having someone to listen and understand" was the number one response and "information about the disability" was number two.

Because of confidentiality, families were not asked to self identify on the written family survey. For that reason, there is no way to separate the rural and urban reports. Question number 1 was specific to family network veteran parent training. Eleven items were provided for family members to check regarding areas of training that they felt would be most important for veteran parents. Families ranked "information about community resources" first at 83%. "Orientation to the Family-to-Family Network Program" was second at 74% followed by "information regarding positive philosophy about persons with disabilities" and "information about disability oriented organizations" were both third at 65%.

Written family survey question number 2 also listed responses for families to check regarding the most effective method(s) of recruiting veteran parents. Tied at 30% were both (b) only, "being asked by an agency representative that works with families with children with disabilities" and (a) and (b) "being asked by another parent(s)" in addition to an agency representative.

**Research Question number 2: What programs/agencies currently provide family-to-family networking?**

Interview Questions numbers 5 and 6 provided a family perspective to this question. Again, rural and urban issues were extrapolated for comparison.

**Interview Question 5**

Families were asked to report where they currently found the necessary support to assist them in raising their child with a disability. The most frequent response, from both groups, indicated support was received from Infant Development/Tracking. Parents from both groups responded that they received some of their support from their families (including spouse, their disabled child's siblings, parents, and other family members). Both focus group families stated they found some of their necessary support from other parents of children with disabilities as well as from friends and co-workers.

Health care professionals and therapists were also mentioned by both groups as a source of informational and emotional support. Parents from both rural and urban groups reported they found some of their support through their children's day care, preschool, and Head Start staff as well as through their children's teachers and school counselors.

Across the board from both groups, the focus group parents responded they found some of their necessary support from organizations such as North Dakota Department of Human Services, Pathfinders, Child Evaluation and Treatment Program at Altru Health Institute, and the State Developmental

Center. Others stated they received some of their financial support from SSI, Medicaid, Medical Assistance, and the Shriners, both locally and through the Shriners Hospital.

Again, uniform to both focus groups, parents stated they looked to God, to their church, religious support groups, and their faith for some of their support. Some found their support from advocacy organizations, such as OPTIONS, Federation of Families, and other support groups.

#### **Interview Question 6**

This question asked families to share something valuable that they had learned from another family with a child with a disability. Here the responses from both groups of families were as varied as the focus group participants were. Some of the comments were along the line of emotional and mental health issues. Suggestions such as “take one day at a time,” and “it’s ok to cry, you’ll get through it,” “hold on to your humor,” and “it’s ok not to like your child and have negative thoughts.” Some of the advice offered by other families with children with disabilities dealt more with day-to-day life. These suggestions ranged from “you don’t have to fold the underwear” to “you have to voice your opinions and concerns regarding your child from the very start.”

Research question number 3 was not addressed with the families with children with disabilities. This question pertained to collaborative opportunities for providers and agencies.

## CHAPTER V

### DISCUSSION AND CONCLUSION

From the results of this research, it was concluded that survey assessment and interviewing are valuable tools for measuring and identifying perceptions and priorities. Addressed throughout this research are two independent but related instruments whose final objective was to provide a foundation for planning a statewide family-to-family network. The survey instrument to agencies and providers elicited information as to the current efforts for family-to-family support in North Dakota and additionally to identify collaborative opportunities. The second instrument, focus interview discussion groups involving families with children with disabilities, was designed to identify current supports as well as potential types of supports that may be important for a statewide system. The results of this research will be of particular interest to the funding source; North Dakota Developmental Disabilities Division and also families with children with disabilities in the state of North Dakota. At the conclusion of the research, a total of \$14,000 was unused and returned to the state.

The overall return rate for the survey instrument to agencies and providers was 22.5%. Low return rate may be, in part, attributed to several factors. First, since the mailing list included family practitioners, general practitioners, and

physicians who specialize in pediatrics and orthopedics as well as clinical sites and hospitals, there was an overlap in distribution as many of these practitioners worked in those clinics or hospitals. Each clinical site and hospital may have had different regulations and procedures regarding the distribution of the surveys and, in fact, we received both written notice and phone contacts as to the overlap. A number of surveys were returned incomplete with a note indicating that as a general or family practice physician they never saw patients with disabilities. The researcher questioned the validity of this statement, as many of these practitioners were the only family or general practice physicians in that particular area. Perhaps these physicians did not see patients for concerns directly regarding their disabilities, but they did potentially have the opportunity to impact the family in regard to the disability. Additionally, a few were returned indicating that the physician was either retired from clinical practice or on leave. Due in part to these factors, the researcher believes that the return rate was somewhat higher than 22.5%. It would have been preferred to have more input concerning the current efforts and opportunities for collaboration, but the information received provided us with enough data from which to draw relevant, helpful conclusions.

Principle findings regarding referrals were consistent between agencies/providers and data from the National Parent-to-Parent survey administered between 1989-1993.<sup>26</sup> The number one referral source for the agencies/providers as well as the one identified in the National Parent-to-Parent study was medical practitioners, followed by social workers and thirdly, friends or

relatives. This information will be crucial to the design and implementation of a statewide program.

The basis for matching families was also consistent between both subject groups. Both the first and second priority for matching families with children with disabilities was identical for agencies/providers and families with children with disabilities. These findings corresponded with and supported the literature reviewed earlier indicating the number one basis for matching was similar disability followed by similar family issues.<sup>1</sup>

As for program supports, families with children with disabilities ranked having someone to listen and getting information about their family member's disability as their two most important supports. Again, these data were consistent with the National Parent-to-Parent study.

Although 23% of the agencies/providers responding indicated they did some form of matching of families with children with disabilities with other families with children with disabilities, a total of 98% perceived that a statewide family-to-family network would be beneficial for the state of North Dakota.

#### Limitations

A total of 50 parents of children with disabilities participated in the focus groups. Of those, 38 families were represented by mothers only, 2 by fathers only, and 5 families by both parents. A limitation of the study lies in the fact that the researcher did not address whether the child with the disability resided in a single parent household and whether the parent present was the primary caregiver. This certainly might have had implications as to the actual or

perceived level of support for that family. Furthermore, the total number of children in a single parent household as well as proximity to relatives may have compounded that same issue; neither issue was addressed with the focus group participants.

Although selection for inclusion into the focus group was left to the Family Involvement Subcommittee parent representative, the ultimate demographics as to the age of the child with the disability did not represent the age group 12 to 18. Thus, this project ultimately failed to address concerns or needs unique to that age group.

Many children with disabilities have multiple diagnoses and some have yet to receive a diagnosis. Consequently, it is difficult if not impossible to identify totally what types of disabilities were represented in the focus groups.

Of the nine questions posed to families of children with disabilities, three asked families to identify obstacles or barriers relevant to raising a child with a disability, one was to identify demographics, and the remaining five dealt with supports for those families. Although the researcher was able to gather information as to the priorities regarding the design of a formal network for family support, it is felt that it would have been relevant to have gathered information regarding ability to access support. Some factors such as physical or financial constraints may have been important to identify to be responsive to the needs of families in the rural environment.

Possibly, the same interviewer and recorder should have participated in all seven sessions in order to provide more intra-interviewer consistency. Although



the data presented are quantitative in nature, much of the impact of the focus interview group dynamics is left unreported. The parents this researcher lead in Grafton stayed an additional two hours to exchange phone numbers and provide names and information to each other regarding resources for their families.

When one mother shared that her son was newly diagnosed and she did not know what services were available for her family, parents in the group reached out and offered emotional and informational support. She left that evening with multiple resources. It seemed that the very support network under study was actively working at these sessions. For many family members, it was their first opportunity to visit with another family with a child with a disability. Some even reported that they knew of other families in their community but had not had the chance to talk. In visiting with other interviewers, this researcher realized that the group facilitated was not unique in the fact that families reached out and provided support to each other.

### Conclusion

The initial charge of the RFP was to determine the need and feasibility of a family-to-family network for North Dakota. There are a variety of programs and agencies within the state of North Dakota which provide certain family support services. However, no organized, coordinated, statewide family-to-family network or process for systematically matching experienced (veteran) parents of a family member with a disability with new parents or family members who are just beginning to meet the challenges of a disability within their family exists in the state of North Dakota. Agencies/providers and families with children with

disabilities agree that the need exists and that the implementation of a statewide network would be beneficial for both families and providers. Thus, the null hypothesis is rejected.

## ADDENDUM

The research findings of this feasibility study were described in detail on a Project Overview and Research Findings report submitted to the North Dakota Human Services and the Family Involvement Subcommittee of the North Dakota Interagency Coordinating Council in March of 1998. The findings have resulted in a Recommendation and Implementation Plan dated April 1, 1998, submitted by Peggy Mohr, Ph.D., P.T., Linda Olson, Ed.D., Assistant Director of Curriculum Development, UNDSOM Office of Academic Affairs, and Laurie Betting, graduate student in physical therapy at the University of North Dakota.

Numerous grants have been written and RFP's answered pursuing funding for this network. North Dakota Maternal Child and Health, under the direction of Tammy Gallup-Milner, has provided \$10,000 for parent training and administrative costs associated with start-up of a statewide family-to-family network. SSDI, under the supervision of Terry Bohn, added an additional \$5000 for the formation of a database and associated hardware. At this critical point, the North Dakota Department of Human Services Developmental Disabilities Division, under the direction of Deb Baldson, provided funding for Betsy Santelli of the aforementioned Beach Center and Polly Arango, National Director of Family Voices, to present at the 3<sup>rd</sup> Annual North Dakota Early Intervention Institute on September 11-12, 1998, in Mandan, North Dakota. Arrangements

for these speakers was facilitated by Donene Feist, a parent of a child with a disability and member of the Family Involvement Subcommittee, during the National Parent-to-Parent Conference in Atlanta, Georgia, in June of 1998. Concurrently, funding was provided through the same agency for families with children with disabilities to attend the Mandan conference. It was at this conference that families were updated on the findings of this research and educated as to the role of a veteran parent in a family support network. A total of 48 family members were in attendance, and before the weekend was over, 100% of them indicated a desire to be involved in the formation of a statewide network. This portion of the conference was coordinated by Donene Fiest and Laurie Betting and sponsored by the Family Involvement Subcommittee and the Disabilities Division of the North Dakota Department of Human Services.

On September 15, 1998, Deb Baldson called to inform Peg Mohr that a \$50,000 contract was awarded to UND for the implementation of a North Dakota Family-to-Family Network as outlined in the April 1, 1998, plan and, furthermore, that it would be a line item in the upcoming state budget requests. The network is born.

## APPENDIX A

☐ EXPEDITED REVIEW REQUESTED UNDER ITEM \_\_\_\_ (NUMBER(S)) OF HHS REGULATIONS  
☒ EXEMPT REVIEW REQUESTED UNDER ITEM 2 (NUMBER(S)) OF HHS REGULATIONS

**UNIVERSITY OF NORTH DAKOTA  
 HUMAN SUBJECTS REVIEW FORM  
 FOR NEW PROJECTS OR PROCEDURAL REVISIONS TO APPROVED  
 PROJECTS INVOLVING HUMAN SUBJECTS**

**PRINCIPAL**

INVESTIGATOR: Laurie Lacrosse-Bruggeman TELEPHONE: (701) 775-6904 DATE: June 20, 1997

ADDRESS TO WHICH NOTICE OF APPROVAL SHOULD BE SENT: 2504 Cherry Street Grand Forks, ND 58201

SCHOOL/COLLEGE: School of Medicine DEPARTMENT: Physical Therapy PROPOSED PROJECT DATES: 7/ 1997 - 12/ 1997

PROJECT TITLE: Proposal: A Program For a Family to Family Statewide Network and Support System For Families With Disabilities

FUNDING AGENCIES (IF APPLICABLE): North Dakota Department of Human Services : Developmental Disabilities Unit

**TYPE OF PROJECT:**

DISSERTATION OR

☒ NEW PROJECT ☐ CONTINUATION ☐ RENEWAL ☐ THESIS RESEARCH ☒ STUDENT RESEARCH PROJECT

☐ CHANGE IN PROCEDURE FOR A PREVIOUSLY APPROVED PROJECT

DISSERTATION/THESIS ADVISER, OR STUDENT ADVISER: Peggy M. Mohr, Ph.D., P.T.

INVOLVES A COOPERATING

PROPOSED PROJECT: ☐ INVOLVES NEW DRUGS (IND) ☐ INVOLVES NON-APPROVED USE OF DRUG ☒ INSTITUTION

IF ANY OF YOUR SUBJECTS FALL IN ANY OF THE FOLLOWING CLASSIFICATIONS, PLEASE INDICATE THE CLASSIFICATION(S):

☐ MINORS (<18 YEARS) ☐ PREGNANT WOMEN ☐ MENTALLY DISABLED ☐ FETUSES ☐ MENTALLY RETARDED

☐ PRISONERS ☐ ABORTUSES ☐ UND STUDENTS (>18 YEARS) (Not applicable)

IF YOUR PROJECT INVOLVES ANY HUMAN TISSUE, BODY FLUIDS, PATHOLOGICAL SPECIMENS, DONATED ORGANS, FETAL MATERIAL, OR PLACENTAL MATERIALS, CHECK HERE ☐ (Not applicable)

1. ABSTRACT: (LIMIT TO 200 WORDS OR LESS AND INCLUDE JUSTIFICATION OR NECESSITY FOR USING HUMAN SUBJECTS.)

The purpose of this study is to determine the feasibility of a family-to-family network within the state of North Dakota and will result on the development of a three (3) year plan for the implementation of such a network. The model for this family support network would include a process of matching experienced or "veteran" parents of a family member with a disability with parents who are just beginning to meet the challenges of a disability within the family. It is the intent of this research that the design and implementation of this plan be responsive to the needs of the families in a rural environment. It is also the intent of this research to enhance current efforts to provide family support services and promote interagency collaboration. Data will be obtained through the use of survey instruments distributed to agencies and support groups working with families with children ages birth through eighteen (18). As one of the prime objectives is to identify programs and/or agencies that are currently providing family-to-family networking efforts, those providers must be incorporated as participants in this study.

**PLEASE NOTE:**

Only information pertinent to your request to utilize human subjects in your project or activity should be included on this form. Where appropriate attach sections from your proposal (if seeking outside funding).

**2. PROTOCOL:** (Describe procedures to which humans will be subjected. Use additional pages if necessary.)

A survey questionnaire that addresses issues associated with family-to-family networking efforts, training provided to families, resources and current funding will be sent to agencies and support groups within the state of North Dakota that work with families with children birth through eighteen (18) that have disabilities. The initial mailing will be followed up with a reminder notice in approximately two weeks and a second mailing to non-respondents at four weeks.

Subjects will be requested to provided information regarding: a) current family-to-family support efforts, b) types of support provided, c) resources available for inclusion/dissemination for a statewide family-to-family network.

**3. BENEFITS:** (Describe the benefits to the individual or society.)

It is anticipated that the results of this study will: a) provide information regarding the type of network design that would be most valuable, b) identify the method(s) of accessing the network that would be most effective, c) ascertain type(s) of network support that would be most beneficial and identify programs and/or agencies that are currently providing family-to-family networking efforts. It is hoped that this research will provide a foundation for the development of a three (3) year plan for the implementation of a multi-agency collaborative family-to family network for families of the state of North Dakota.

**4. RISKS:**

(Describe the risks to the subject and precautions that will be taken to minimize them. The concept of risk goes beyond physical risk and includes risks to the subject's dignity and self-respect, as well as psycho-logical, emotional or behavioral risk. If data are collected which could prove harmful or embarrassing to the subject if associated with him or her, then describe the methods to be used to insure the confidentiality of data obtained, including plans for final disposition or destruction, debriefing procedures, etc.)

Agencies and support groups will make the decision to participate on the study by completing the survey and returning it by mail. Data will be coded so that respondents information will not be readily identifiable. Results of the study will be reported in a manner that does not allow identification of the data with the respondents. All data will be stored in a locked cabinet in the office of Dr. Peggy Mohr for a period of three years following the completion of this study.



- 5. CONSENT FORM:** A copy of the **CONSENT FORM** to be signed by the subject ( if applicable ) and/or any statement to be read to the subject should be attached to this form. If no **CONSENT FORM** to be used, document the procedures to be used to assure that infringement upon the subject's rights will not occur.

Describe where signed consent forms will be kept and for what period of time.

As participants will not be required to sign a consent form since they can refuse to participate by not returning the survey. Data will be retained for three (3) years following completion of this study in a locked cabinet in my advisor's, Peggy Mohr, office.

- 6.** For **FULL IRB REVIEW** forward a signed original and thirteen (13) copies of this completed form, and where applicable, thirteen (13) copies of the proposed consent form, questionnaires, etc. and any supporting documentation to:

Office of Research & Program Development  
University of North Dakota  
Box 8138, University Station  
Grand Forks, North Dakota 58202

On campus, mail to: Office of Research & Program Development, Box 134, or drop it off at Room 101 Twamley Hall.

For **EXEMPT** or **EXPEDITED REVIEW** forward a signed original and a copy of the consent form, questionnaires, etc. and any supporting documentation to one of the addresses above.

-----

The policies and procedures on Use of Human Subjects of the University of North Dakota apply to all activities involving use of Human Subjects performed by personnel conducting such activities under the auspices of the University. No activities are to be initiated without prior review and approval as prescribed by the University's policies and procedures governing the use of human subjects.

**SIGNATURES:**

Burris Lacrosse-Duggemus DATE: 6/23/97  
Principal Investigator

Peggy Mohr DATE: 6/23/97  
Project Director or Student Adviser

\_\_\_\_\_  
Training or Center Grant Director

## APPENDIX B

**Helping Hands**



Across North Dakota  
Family to Family Network

*Network by Minnesota Resources*

**Survey of  
Family-to-Family  
Support Activities  
in North Dakota**

This survey is being conducted to identify current Family-to-Family Support Activities and to determine the feasibility of developing a statewide Family-to-Family Network. As an agency or program providing services to families with children who have disabilities, your assistance and response to the following questions would be greatly appreciated!

**Demographic Information:**

Name of Program/Support Group/Agency: \_\_\_\_\_

Address: \_\_\_\_\_

Phone/Fax: \_\_\_\_\_

Name of person completing survey: \_\_\_\_\_

1. You are a: (Check all that apply)
- ☐ a. Parent of a family member
  - ☐ b. Practitioner in a disability field
  - ☐ c. Paid office-support staff member
  - ☐ d. Volunteer within your program
  - ☐ e. Other \_\_\_\_\_

2. Mission statement or purpose of program/agency/support group: (You may attach extra sheet, if desired)

3. Do you publish any newsletters or periodicals?

☐ Yes  
☐ No

If yes, please list titles: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

4. Is information available in non-English languages?

☐ Yes  
☐ No

If yes, please specify: \_\_\_\_\_

\_\_\_\_\_

5. Is information available in non-print format?

☐ Yes  
☐ No

6. Number of members or clients receiving services:

\_\_\_\_\_

7. Please indicate each of the following which apply:

If applicable, estimated annual cost:

☐ Membership fees \_\_\_\_\_  
☐ Fixed rate dues/fees \_\_\_\_\_  
☐ Variable fee/sliding rate \_\_\_\_\_  
☐ No charge \_\_\_\_\_

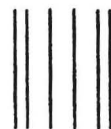
8. Which of the following best describes the type of community in which your program/agency/support group operates?

☐ a. City between 25,000 and 100,000 population  
☐ b. Town between 2,500 and 25,000 population  
☐ c. Small town of 2,500 or less population  
☐ d. Rural locale but not farm  
☐ e. Farm

**Support Activities Questions:**

9. Please indicate your referral source: (Check all that apply)
- ☐ a. Medical practitioners/facilities
  - ☐ b. Early intervention programs
  - ☐ c. Social services practitioners
  - ☐ d. Development disabilities care management
  - ☐ e. Education practitioners
  - ☐ f. Friends or relatives
  - ☐ g. Religious organizations
  - ☐ h. Other (please specify): \_\_\_\_\_
10. Funding Sources: Please list the approximate percentage of funding that comes from each of the sources that apply:
- ☐ a. Sponsoring agency \_\_\_\_\_ %
  - ☐ b. Fees \_\_\_\_\_ %
  - ☐ c. Local or state grants \_\_\_\_\_ %
  - ☐ d. Federal grants \_\_\_\_\_ %
  - ☐ e. Private donations \_\_\_\_\_ %
  - ☐ f. Fundraising activities \_\_\_\_\_ %
  - ☐ g. Other (please specify): \_\_\_\_\_
11. Do you presently match "new" parents/families with "veteran" or "supporting" parents for support?
- ☐ Yes
  - ☐ No
12. On what basis are families matched? (Check all that apply)
- ☐ a. Families have family members with similar disabilities
  - ☐ b. Families have faced same kinds of problems (legal, medical, educational)
  - ☐ c. Families have family members with a disability who are about the same age
  - ☐ d. Families have about the same number of people in them
  - ☐ e. Families have similar family structures (1-parent/2-parent)
  - ☐ f. Families have about the same education level and income
  - ☐ g. Families have similar cultural/ethnic backgrounds
  - ☐ h. Families live relatively close together
  - ☐ i. Other (please specify): \_\_\_\_\_
  - ☐ j. Not applicable
13. Please tell us how contacts between the "veteran" family and the referred family are usually made. (Check one)
- ☐ a. By telephone
  - ☐ b. In person
  - ☐ c. Other (please specify): \_\_\_\_\_
  - ☐ d. Not applicable
14. Currently, how many families are actively participating in family-to-family support activities? \_\_\_\_\_
15. Please tell us about the types of support provided to the families by families. (Check all that apply)
- ☐ a. Someone to listen and understand
  - ☐ b. Problem solving support
  - ☐ c. Information about the disability
  - ☐ d. Information about living with/caring for a family member
  - ☐ e. Information about community services/resources (respite, etc.)
  - ☐ f. Referrals to other agencies
  - ☐ g. How to find best possible help for the family member
  - ☐ h. Group activities for fun
  - ☐ i. Group activities for support
  - ☐ j. Other (please specify): \_\_\_\_\_
  - ☐ k. Not applicable
16. Do you provide training activities, initially or ongoing, for families?
- ☐ Yes
  - ☐ No
17. Please tell us about the content areas of training provided to families who would serve as "veteran" families? (Check all that apply)
- ☐ a. Orientation to program
  - ☐ b. Positive philosophy about persons with disabilities
  - ☐ c. Self-awareness activities
  - ☐ d. Information about disability organizations
  - ☐ e. Information about financial issues/estate planning
  - ☐ f. Information about community resources
  - ☐ g. Listening and communication skills
  - ☐ h. Planning transition
  - ☐ i. Information about initial reactions to diagnosis

- ☐ j. Skills for working with culturally diverse families  
☐ k. Advocacy and legal issues  
☐ l. Leadership training  
☐ m. Other (please specify): \_\_\_\_\_  
☐ n. Not applicable
18. Would a statewide family-to-family network be beneficial for the state of North Dakota?
- ☐ Yes  
☐ No
19. If so, how do you perceive a statewide family-to-family program operating in North Dakota?
20. What do you see as essential elements for a statewide family-to-family network? (Check all that apply)
- ☐ a. Single entry point for access  
☐ b. Access at the point of need/diagnosis  
☐ c. Orientation about the program  
☐ d. Self-awareness activities  
☐ e. Networking with national family organizations  
☐ f. Training for participating families (communication and listening skills)  
☐ g. Veteran family preparation training  
☐ h. Advocacy training  
☐ i. Social events  
☐ j. Special activities for other "family" members (brothers, sisters, grandparents, childcare providers)  
☐ k. Training to teach current practitioners and students preparing to work with families  
☐ l. Other (please specify): \_\_\_\_\_
21. What resources are available from your program that could be made available for inclusion in a resource library for dissemination to family-to-family programs? (Check all that apply)
- ☐ a. Program brochure  
☐ b. Newsletter  
☐ c. Training material for "veteran" families  
☐ d. Information packets for referred families  
☐ e. Slide/video show  
☐ f. Radio spots  
☐ g. Database of families  
☐ h. Other (please specify): \_\_\_\_\_
22. In what ways could a statewide family-to-family network be of assistance to your organization? (Check all that apply)
- ☐ a. Provide a database of parent volunteers  
☐ b. Serve as a referral resource to connect families  
☐ c. Provide a mechanism to distribute information  
☐ d. Provide access to parent trainers/speakers  
☐ e. Provide referral mechanism for national support groups  
☐ f. Referral source to service providers  
☐ g. Other (please specify): \_\_\_\_\_
23. What additional resources might potentially be available to assist in the formation and/or support of a statewide family-to-family network? (Check all that apply)
- ☐ a. Speaker listening  
☐ b. Office and or meeting space  
☐ c. Office equipment to maintain records and coordinate network  
☐ d. Underwriting of start-up and initial operating costs  
☐ e. Staff for consultation as resource persons and for training of parent volunteers  
☐ f. Assistance with public awareness and referrals  
☐ g. A not-for-profit status of an established agency to qualify for funding  
☐ h. Assistance with fund raising and grant writing  
☐ i. A family-to-family telephone line for receiving referrals  
☐ j. Cash contributions  
☐ k. Other (please specify): \_\_\_\_\_



NO POSTAGE  
NECESSARY  
IF MAILED  
IN THE  
UNITED STATES

**BUSINESS REPLY MAIL**

FIRST-CLASS MAIL PERMIT NO. 225 GRAND FORKS, ND

POSTAGE WILL BE PAID BY ADDRESSEE

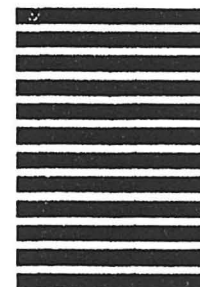
5293-1212

Bureau of Educational Services & Applied Research

University of North Dakota

PO Box 7053

Grand Forks ND 58202-9988



84

24. How do you address issues of confidentiality?

Additional Comments:

PLEASE FOLD YOUR QUESTIONNAIRE SO THE RETURN  
ADDRESS SHOWS AND SECURE THE SHEETS WITH TAPE -  
DO NOT STAPLE. THANK YOU.

## APPENDIX C

July 15, 1997

My name is Laurie Lacrosse-Bruggeman, and I am a physical therapy student at the University of North Dakota and a parent of a child with a disability. In fulfillment of an independent study requirement, I am conducting research, funded by the Department of Human Services of North Dakota, that will determine the feasibility of a statewide family-to-family network. The results of this study will serve as the foundation for the development of a three (3) year plan for the implementation of such a network.

The model for this family support network would include a process of systematically matching "veteran" parents of a family member with a disability with "new" parents who are just beginning to meet the challenges of a disability within the family. Because veteran parents have "been there" and experienced the many intense emotions that accompany a disability, they are in a unique position to establish a meaningful bond with the referred parent. As a component of this model, veteran parents receive training in techniques and strategies to support other parents.

It is the intent of this project to enhance current efforts to provide family support services and promote interagency collaboration. To do so, it is necessary to identify programs and agencies currently providing family support services within the state, opportunities for interagency collaboration, and potential funding sources.

As an agency or support group that interacts with families with children with disabilities, you are being asked to complete the enclosed survey. Your response is crucial to the success of this study. **Please take the time to complete the enclosed survey and return it in the postage paid envelope provided.** Completing the survey is optional, and by completing and returning the survey you are consenting to be in this study. Results of the study will be reported in a manner that does not allow identification of the data with the respondents. All data will be stored in a locked cabinet in the office of Dr. Peggy Mohr for a period of three (3) years following the completion of this study.

**Please complete and return the survey by August 15, 1997.** It will take approximately ten (10) minutes to complete.

If you have any questions regarding the enclosed survey, you may contact me at the following address or my academic advisor, Peggy Mohr.

Laurie Lacrosse-Bruggeman  
2504 Cherry Street  
Grand Forks, ND 58201  
(701) 775-6904

Peggy M. Mohr, Ph.D., P.T.  
Department of Physical Therapy  
University of North Dakota School of Medicine  
P.O. Box 9037  
Grand Forks, ND 58202-9037  
(701) 777-3689





**Setting up the Focus Group Interview Session**  
(Parent Coordinator)

1. Secure the names of other parents in your geographical area who have children with disabilities
2. Contact your interviewer and establish the date, time, and location for the focus interview.
3. Call each parent on the list and explain the purpose of the meeting. Use the parent notification letter as a guide. Discuss their willingness to participate in the interview. Continue calling until you have ten parents who have consented to participate in the session.
4. Submit the listing of parents who have consented to participate to Peggy Mohr, Ph.D., P.T., UND-PT, P.O. Box 9037, Grand Forks, ND 58202-9037. (A copy of your list of participants will be forwarded to your interviewer by our office.)
5. Arrange to attend the session. Try to be there at least 30 minutes early to greet the parents who have been invited.

## APPENDIX E



Across North Dakota  
Family to Family Network

*Artwork by Shannon Wirrenga*

SCHOOL OF MEDICINE & HEALTH SCIENCES  
DEPARTMENT OF PHYSICAL THERAPY  
501 NORTH COLUMBIA ROAD  
P.O. BOX 9037  
GRAND FORKS, NORTH DAKOTA 58202-9037  
(701) 777-2831  
FAX (701) 777-4199

July 27, 1997

Dear (parent),

Thank you for consenting to attend a group focus interview on family support needs. The session will be held on **Insert Date and Time** at **Location**. The address is **Address**.

Parents with children with disabilities that serve on North Dakota's Family Involvement Subcommittee are assisting us in researching the feasibility of creating a statewide, coordinated family-to-family support network in North Dakota. As part of this process, several focused interview sessions will be held across the state. The focus interview process is being utilized as a technique to gather data specifically on family support needs in North Dakota. During each session, parents will have the opportunity to discuss experiences and issues within their family that have influenced the family's ability to cope with having a disability affect a child. In addition, parents will be asked to address issues or concerns they have regarding access to community and social supports, the influence of rural environments, and the essential components of a family to family support network.

The data generated by these interviews will be used in developing a plan for a statewide family to family network. It is our hope that this network will respond specifically to the needs and concerns identified in North Dakota. In this process, all responses by parents will be kept confidential and the results of this study will be reported in a manner that does not allow identification of the data with the respondents.

The interview session will be informal. Please dress casually. Be prepared to sit back, make new friends, have some coffee and cookies, and visit about what is needed by your family to get through some of the trials that you face. If you have any questions prior to the session, please call me at (701) 777-3689 or Linda Olson at (701) 777-3953. Again, thank you for your willingness to participate in this group interview.

Sincerely,

Peggy Mohr, Ph.D, P.T.  
Linda Olson, Ed.D.



## APPENDIX F

EXPEDITED REVIEW REQUESTED UNDER ITEM      (NUMBER[S]) OF HHS REGULATIONS  
  X   EXEMPT REVIEW REQUESTED UNDER ITEM   2   (NUMBER[S]) OF HHS REGULATIONS

**UNIVERSITY OF NORTH DAKOTA  
HUMAN SUBJECTS REVIEW FORM  
FOR NEW PROJECTS OR PROCEDURAL REVISIONS TO APPROVED  
PROJECTS INVOLVING HUMAN SUBJECTS**

**PRINCIPAL**

**INVESTIGATOR:** Laurie Lacrosse-Bruggeman **TELEPHONE:** (701) 775-6904 **DATE:** July 22, 1997

**ADDRESS TO WHICH NOTICE OF APPROVAL SHOULD BE SENT:** 2504 Cherry Street Grand Forks, ND 58201

**SCHOOL/COLLEGE:** School of Medicine **DEPARTMENT:** Physical Therapy **PROPOSED PROJECT DATES:** 8/ 1997 – 12/ 1997

**PROJECT TITLE:** Proposal: A Program for a Family to Family Statewide Network and Support System for Families with Disabilities

**FUNDING AGENCIES (IF APPLICABLE):** North Dakota Department of Human Services : Developmental Disabilities Unit

**TYPE OF PROJECT:**

DISSERTATION OR

     NEW PROJECT     X   CONTINUATION        RENEWAL        THESIS RESEARCH     X   STUDENT RESEARCH PROJECT

     CHANGE IN PROCEDURE FOR A PREVIOUSLY APPROVED PROJECT

**DISSERTATION/THESIS ADVISER, OR STUDENT ADVISER:** Peggy M. Mohr, Ph.D., P.T.

INVOLVES A COOPERATING

**PROPOSED PROJECT:**      INVOLVES NEW DRUGS (IND)        INVOLVES NON-APPROVED USE OF DRUG     X   INSTITUTION

**IF ANY OF YOUR SUBJECTS FALL IN ANY OF THE FOLLOWING CLASSIFICATIONS, PLEASE INDICATE THE CLASSIFICATION(S):**

     MINORS (<18 YEARS)        PREGNANT WOMEN        MENTALLY DISABLED        FETUSES        MENTALLY RETARDED

     PRISONERS        ABORTUSES        UND STUDENTS (>18 YEARS)

**IF YOUR PROJECT INVOLVES ANY HUMAN TISSUE, BODY FLUIDS, PATHOLOGICAL SPECIMENS, DONATED ORGANS, FETAL MATERIAL, OR PLACENTAL MATERIALS, CHECK HERE** (Not applicable)

**1. ABSTRACT:** (LIMIT TO 200 WORDS OR LESS AND INCLUDE JUSTIFICATION OR NECESSITY FOR USING HUMAN SUBJECTS.)

The purpose of this study is to determine the feasibility of a family to family network within the state of North Dakota and will result in the development of a three (3) year plan for the implementation of such a network. The model for this family support network would include a process of matching experienced or "veteran" parents of a family member with a disability with parents who are just beginning to meet the challenges of a disability within the family. It is the intent of this research that the design and implementation of this plan would be responsive to the needs of families in a rural environment. It is also the intent of this research to determine the priorities of families regarding a family to family network; the most effective methods of recruitment, training, and mechanism for accessing the network. Data will be obtained through use of focused interviews with families with children with disabilities ages birth through eighteen. Also an optional take hoe survey will be provided at these focused interviews. As one of the prime objectives is to identify the priorities of the families, these families must be incorporated as participants in this study.

**PLEASE NOTE:**

Only information pertinent to your request to utilize human subjects in your project or activity should be included on this form. Where appropriate attach sections from your proposal (if seeking outside funding).

**2. PROTOCOL:** (Describe procedures to which humans will be subjected. Use additional pages if necessary.)

Focused interviews that address issues associated with priorities of families regarding a family-to-family network; the most effective methods of recruitment, referral, training and mechanisms for accessing the network will be conducted throughout the state of North Dakota representing a variety of disability areas, who have experience of varying lengths in dealing with disabilities and who have children of varying ages ranging from birth through eighteen.

Subjects will voluntarily attend a focused interview session that includes a total of eight to ten family members of families with a child with a disability. Each family represented will be given the opportunity to respond to questions regarding current support systems and needs of their family. At the conclusion of the sessions a survey addressing additional components for the organization of a family-to-family network will be made available for those that would be willing to participate and self identification will not be necessary.

**3. BENEFITS:** (Describe the benefits to the individual or society.)

It is anticipated that the results of this study will: a) provide information regarding the type of network design that would be most valuable, b) identify the method(s) of accessing the network that would be most effective, c) ascertain type(s) of network support that would be most beneficial and identify the most effective method(s) of recruitment for family-to-family networking efforts. It is hoped that this research will provide a foundation for the development of a three (3) year plan for the implementation of a multi-agency collaborative family-to-family network for families of the state of North Dakota.

**4. RISKS:** (Describe the risks to the subject and precautions that will be taken to minimize them. The concept of risk goes beyond physical risk and includes risks to the subject's dignity and self-respect, as well as psycho-logical, emotional or behavioral risk. If data are collected which could prove harmful or embarrassing to the subject if associated with him or her, then describe the methods to be used to insure the confidentiality of data obtained, including plans for final disposition or destruction, debriefing procedures, etc.)

Family members will make the decision to participate in the study by attending the focused interview and/or completing the survey and returning it in the mail. Data will be coded so that the respondents information will not be readily identifiable. Results of the study will be reported in a manner that does not allow identification of the data with the respondents. All data will be stored in a locked cabinet in the office of Dr. Peggy Mohr for a period of three years following the completion of this study.



**5. CONSENT FORM:**

A copy of the **CONSENT FORM** to be signed by the subject (if applicable) and/or any statement to be read to the subject should be attached to this form. If no **CONSENT FORM** is to be used, document the procedures to be used to assure that infringement upon the subject's rights will not occur.

Describe where signed consent forms will be kept and for what period of time.

As participants will not be required to sign a consent form since they can refuse to participate by not attending the focused interview, by not the answering questions at the session or by not picking up or returning the survey. Data will be retained for three (3) years following the completion of this study in a locked cabinet in my advisor's, Peggy Mohr, office.

6. For **FULL IRB REVIEW** forward a signed original and thirteen (13) copies of this completed form, and where applicable, thirteen (13) copies of the proposed consent form, questionnaires, etc. and any supporting documentation to:

Office of Research & Program Development  
University of North Dakota  
Box 8138, University Station  
Grand Forks, North Dakota 58202

On campus, mail to: Office of Research & Program Development, Box 134, or drop it off at Room 101 Twamley Hall.

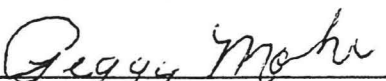
For **EXEMPT** or **EXPEDITED REVIEW** forward a signed original and a copy of the consent form, questionnaires, etc. and any supporting documentation to one of the addresses above.

-----

The policies and procedures on Use of Human Subjects of the University of North Dakota apply to all activities involving use of Human Subjects performed by personnel conducting such activities under the auspices of the University. No activities are to be initiated without prior review and approval as prescribed by the University's policies and procedures governing the use of human subjects.

**SIGNATURES:**

 **DATE:** 7-22-97  
Principal Investigator

 **DATE:** 7-22-97  
Project Director or Student Adviser

\_\_\_\_\_  
**DATE:**

## APPENDIX G

**Questions:**

As we address each question, we will rotate who will provide the initial response. The first question is: (Read question), and I would like (Name of Participant) to respond and we will follow around the room in this direction (indicate direction).

- 1 Tell me about your family. I'd like to know how many children you have, their ages, sex, and where they go to school. I'd also like to know a little about your family's pastimes, hobbies, or favorite ways of spending free time together.
- 2 Tell me about your child who has a disability. How long have they had that diagnosis? What is the nature of the disability and how does it impact on family members at home and in the community?
- 3 I want you to try to think of a difficulty, barrier, or obstacle that you and your child with a disability have had to face in regard to an issue relevant to your home life or community access. Tell us about the issue and what you did to resolve the crisis or situation.
- 4 What do you view as the greatest challenges in being the parent of a child with a disability?
- 5 Where do you currently find the necessary supports to assist you in your role as parent to your child with a disability? Examples of supports consist of friendships, advice, guidance, access to information, financial assistance, etc.
- 6 Please try to remember something valuable that you learned from another parent of a child with a disability. Please tell us about the circumstances surrounding that contact, what was said or done, and what you learned.
- 7 If you could create your own system for helping other parents rear and educate their child with a disability, what types of supports and assistance would you build into your program?
- 8 If we were to have a formal program utilizing other parents, who would you like to have dialogue with? Similar disabilities? Similar problems, etc.?
- 9 From all of the ideas that have been generated this evening, I want you to think of the one support that you feel was, or would have been, most valuable to you and your family. Please share with us what you view as the single most important issue.

**Conclusion:**

Prior to concluding the session, I would like to ask our recorder if she has any comments or if there are any questions or responses that she would like to have clarified by the participants.

Also at this time we would like to take the opportunity to ask you if you would be willing to take a questionnaire home with you regarding the set up and operation of a family-to-family network. The questionnaire includes a SASE, which we would like returned no later than (1 week out). You can pick them up at the door from (recorder).

In concluding our session this evening, we would like to thank each of you for participating. Your ideas and input are extremely valuable and we appreciate your willingness to take time out of your busy schedules to share them with us.

Thank you and have a safe drive home."

## APPENDIX H

Alternative Focus Interview Questions

- 1) What are your priorities in regard to a family to family network?
  - a) Someone to listen and understand
  - b) Problem solving support
  - c) Information about the disability
  - d) Information about living and caring for family member
  - e) Information about community services and resources
  - f) Referrals to other agencies
  - g) Group activities
  - h) Other
- 2) Where do you go for information about your child's disability?
- 3) What would be the best mechanism for accessing the network?
- 4) Do you have a need for non-English or non-print format?
- 5) What do you see as unique needs of the rural families?
- 6) What are your priorities for "matching"?
  - a) Similar disabilities
  - b) Similar problems (medical, legal, educational)
  - c) Children about the same age
  - d) Similar number of family members
  - e) Similar family structures (1-parent, 2-parent)
  - f) Similar education and income level
  - g) Similar cultural/ethnic background
  - h) Live relatively close together
- 7) How would you like to meet?
  - a) Phone
  - b) Face-to-face
- 8) What do you expect as types of support?
- 9) What types of training would you like?
- 10) How soon would you be willing to serve as a veteran parent?
- 11) What would be the most effective method of recruiting veteran parents?
- 12) Do you think your entire "family" might like to access the network; other children, grandparents, childcare providers?

## APPENDIX I

### Focused Interview Parent Participants:

Thank you for your willingness to assist us in this research to identify the priorities of families like yours with children with disabilities. You are the experts in meeting the sometimes challenging day to day needs of your child and your entire family. It is this resourcefulness that we are attempting to draw upon during the group interview process. Due to time constraints, we were not able to address all areas of concern during the interviews. Therefore, we would appreciate it you would consider completing this short survey

Our research is to determine the feasibility of creating a statewide Family to Family network. This network would include a process of systematically matching "veteran" parents of a family member with a disability with parents who are just beginning to meet the challenges of a disability within the family. We would like your input specifically regarding training programs that are essential for veteran parents and the most effective method of recruiting veteran parents. **Your responses will be confidential no identifying information will be attached to your responses during the reporting process.** We would also like information regarding the willingness of individuals, such as yourself, to serve as veteran parents. (This information is requested on Page Two and should be submitted separately from Page One of the survey.)

Q1. Please tell us about the content areas of training that you feel would be most important to provide?

- ☐ Orientation to the Family to Family Network program
- ☐ Information regarding positive philosophy about persons with disabilities
- ☐ Self-awareness activities
- ☐ Information about disability orientated organizations
- ☐ Information about financial issues/estate planning
- ☐ Information about community resources
- ☐ Listening and communication skills
- ☐ Planning transition(s)
- ☐ Information regarding initial diagnoses
- ☐ Skills for working with culturally diverse families
- ☐ Advocacy and legal issues
- ☐ Other: \_\_\_\_\_

Q2. What would be the most effective method(s) of recruiting veteran parents?

- ☐ Being asked by another parent(s)
- ☐ Being asked by an agency representative that works with families with disabilities
- ☐ Responding to a request for volunteers
- ☐ Other: \_\_\_\_\_

Q3. Who do you feel might benefit from the availability of a Family to Family network other than the family members (parents, children, siblings & grandparents):

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## APPENDIX J



**Instructions for Page Two:**

Please complete this page and return it separately in the self-addressed envelope attached. The preceding page one should be returned in the second envelope in order to preserve confidentiality of your responses.

Please check:

\_\_\_\_\_ I would be willing to serve as a veteran parent. Please contact me at:

Name \_\_\_\_\_

Address: \_\_\_\_\_

Phone No. \_\_\_\_\_(home) \_\_\_\_\_(work)

\_\_\_\_\_ I am currently unable to serve as a veteran parent but would like to be contacted in the future.

I would like to nominate the following parents to serve as veteran parents.

## APPENDIX K

### **Setting up the Focus Group Interview** (Interviewer)

1. Assist in securing the names and addresses of parents from the parent coordinator.
2. Select the time and date for the meeting in collaboration with the Parent Coordinator. Make arrangements for the room, which will be utilized including coffee or soft drinks and cookies. We recommend that you do not use a school for the setting. Other possibilities are churches, banks, or Human Service Center.
3. Make arrangements to have another person attend the session with you to serve as the recorder.
4. Ask the parent coordinator to come to the session 30 minutes early to greet the parents as they arrive.
5. Items that will be needed for the session consist of:
  - a. Tape recorder with a microphone and blank tape(s) for 90 minutes
  - b. Name cards to set on the table in front of each parent, the interviewer, and the recorder.
  - c. Wall chart, which has the questions, printed one question per sheet. In addition to providing visual input during the session, having the questions printed on separate sheets allows for recording the key concepts and issues generated by the parents. The visual cues provide an easy reference for the participants as the session progresses.
  - d. A dry marker for writing on the wall chart.
  - e. Refreshments and snacks: We would appreciate a simple snack (ex: cookies, doughnuts, etc.) and beverage.

## APPENDIX L

## Recording the Session

The note taker or assistant moderator is a critical role in the focus interview process. It is extremely important to have an accurate and comprehensive record of the participants responses. Points to consider prior to, and concurrent with, the session consist of:

1. Double check the tape recorder, microphone, and supply of tapes to ensure that the equipment is available and working. The tapes will provide a wonderful backup to your notes.
2. Arrange to arrive at the session 30 minutes early to assist the moderator in setting up the room and to sound test the equipment.
3. Refer to the attached handout(s) on tips for taking notes and serving as the assistant facilitator. Use the designated Analysis Worksheet Form for recording the content of the session.
4. Sit in a designated location outside the circle and opposite of the facilitator, closest to the door. Greet any parents that arrive late and find them a place to sit.
5. Prepare a sequence of clarification questions as the session progresses. You will be asked at the end of the session whether or not you have anything you would like to add or any questions/responses that you would like to have clarified.
6. Arrange to spend 30 minutes with the facilitator immediately following the session. The debriefing session will be used to review the notes, prepare the diagram of seating arrangements, check the tape recordings, and label and file field notes, tapes, and other materials.
7. Within 24 hours of the session, submit the data to the Project Director. Make a back-up copy of the tape(s) and field notes before sending them in.

## Note Taking

- ◆ **Note taking is a primary responsibility of the assistant moderator**  
The moderator should not be expected to take written notes during the discussion.
- ◆ **Clarity and consistency of note taking**  
Anticipate that others will use your field notes. Field notes sometimes are interpreted days or weeks following the focus group when memory has faded. Consistency and clarity are essential.
- ◆ **Field notes contain different types of information**  
It is essential that this information is easily identified and organized. Your field notes will contain:
  - **Quotes**  
Listen for notable quotes, the well said statements that illustrate an important point of view. Listen for sentences or phrases that are particularly enlightening or eloquently express a particular point of view. Place name or initials of speaker after the quotations. Usually, it is impossible to capture the entire quote. Capture as much as you can with attention to the key phrases. Use three periods ... to indicate that part of the quote was missing.
  - **Key points and themes for each question**  
Typically participants will talk about several key points in response to each question. These points are often identified by several different participants. Sometimes they are said only once but in a manner that deserves attention. At the end of the focus group the assistant moderator will share these themes with participants for confirmation.
  - **Follow-up questions that could be asked**  
Sometimes the moderator may not follow-up on an important point or seek an example of a vague but critical point. The assistant moderator may wish to follow-up with these questions at the end of the focus group.
  - **Big ideas, hunches, or thoughts of the recorder**  
Occasionally the assistant moderator will discover a new concept. A light will go on and something will make sense when before it did not. These insights are helpful in later analysis.
  - **Other factors**  
Make note of factors which might aid analysis such as passionate comments, body language, or non-verbal activity. Watch for head nods, physical excitement, eye contact between certain participants, or other clues that would indicate level of agreement, support, or interest.
- ◆ **Consider using a standardized recording form, such as the "Analysis Worksheet Form"**

## **Systematic Analysis Process**

### **1. Start while still in the group**

- Listen for inconsistent comments and probe for understanding
- Listen for vague or cryptic comments and probe for understanding
- Consider asking each participant a final preference question
- Offer a summary of key questions and seek confirmation

### **2. Immediately after the focus group**

- Draw a diagram of seating arrangement
- Spot check tape recording to ensure proper operation
- Conduct moderator and assistant moderator debriefing
  - Note themes, hunches, interpretations, and ideas
  - Compare and contrast this focus group to other groups
- Label and file field notes, tapes and other materials

### **3. Soon after the focus group--within hours analyze individual focus group.**

- Make back-up copy of tapes and send tape to transcriptionist for computer entry if transcript is wanted
- Analyst listens to tape, reviews field notes and reads transcript if available
- Prepare report of the individual focus group in a question-by-question format with amplifying quotes
- Share report for verification with other researchers who were present at the focus group

### **4. Later--within days analyze the series of focus groups**

- Compare and contrast results by categories of individual focus groups
- Look for emerging themes by question and then overall
- Construct typologies or diagram the analysis
- Describe findings and use quotes to illustrate

### **5. Finally, prepare the report**

- Consider narrative style versus bulleted style
- Use a few quotes to illustrate
- Sequence could be question by question or by theme
- Share report for verification with other researchers
- Revise and finalize report

## Transcribing Focus Group Interviews

### ◆ Use quality play-back equipment

The typist should avoid tape players with small speakers and awkward buttons. Ear phones might be considered. Focus group interview tapes always have background noise and participants will speak with different tones and voice levels--therefore these tapes will require concentration and the best quality play-back equipment that can be obtained. If possible, use equipment with a tape speed control and foot operated back space.

### ◆ Minimize distractions

Type transcripts in a place with minimal distractions or interruptions.

### ◆ Identify moderator statements

Place in bold print the statements and questions of the moderator. If possible, type the name of each speaker followed by their comment. Single space the comments and double space between speakers.

### ◆ Type comments word for word

In real life people do not talk in complete sentences and when typing the transcripts avoid the temptation to add or change the words, correct the grammar, etc. If some of the words are unintelligible then type three periods... to indicate that words are missing from the transcript.

### ◆ Note special or unusual sounds that could help analysis

For example, if there is laughter, loud voices, shouting, etc. be sure that these are noted in the transcript in parenthesis. Make note if someone was interrupted.

### ◆ Allow sufficient time

Typically it takes about eight hours to type one hour of tape. But the time will vary with typist speed, the quality of the tape recording, the length of the session, the experience of the typist with focus groups, and the complexity of the topic.



## Reporting Focus Group Results

### ◆ Use a communications strategy

Rather than thinking of "a report", think of what type of communication strategy is needed. A variety of reports might be used to keep people informed. Consider: e-mail messages, postcards, phone calls, bulleted summaries, selected quotes, moderator comments, mid-project or final project reports, personal visits by members of the research team, etc.

### ◆ Use an appropriate reporting style that the client finds helpful and meets expectations

Ask users what kind of report would be helpful to them. What information are they looking for? What are the expectations and traditions of reports within the organization?

### ◆ Strive for enlightenment

Reports should raise the level of understanding of the client. The purpose is more to enlighten and convey new insights as opposed to repeating common knowledge which is already known by the sponsor of the study.

### ◆ Make points memorable

Help client remember the key points by limited the number of points you highlight. Too many points diminish overall impact. Begin with most important points and follow with lesser important points.

### ◆ Use narrative or bulleted format

Written reports can follow either a narrative format or a bulleted format. Don't surprise the client with a format different from what was expected.

### ◆ Give thought to the oral report

Oral reports should be brief, clear and concise. In addition, oral reports should allow opportunity for questions, indicate why the study is important and why the findings are meaningful, begin with the most important findings, and engage the listener in an active manner.

## APPENDIX M



Across North Dakota  
Family to Family Network Project

**Focus Interview Analysis Worksheet:**

Date of Focus Group Interview \_\_\_\_\_

Parent Coordinator: \_\_\_\_\_

Number of Participants: \_\_\_\_\_

Location: \_\_\_\_\_

Interviewer: \_\_\_\_\_

Recorder: \_\_\_\_\_

**Q. 1** Brief Summary/Key Points

Notable Quotes

#1 Name: City: # of Children, ages & gender Schools attended:	
#2 Name: City: # of Children, ages & gender Schools attended:	
#3 Name: City: # of Children, ages & gender Schools attended:	
#4 Name: City: # of Children, ages & gender Schools attended:	
# 5 Name: City: # of Children, ages & gender Schools attended:	

**Q 1 Continued**

# 6 Name: City: # of Children, ages & gender Schools attended:	
# 7 Name: City: # of Children, ages & gender Schools attended:	
#8 Name: City: # of Children, ages & gender Schools attended	
# 9 Name: City: # of Children, ages & gender Schools attended:	
#10 Name: City: # of Children, ages & gender Schools attended	

**Q. 2****Brief Summary/Key Points****Notable Quotes**

<p># 1 Disability:</p> <p>Length of Diagnosis:</p> <p>Impact on:</p> <p>a) family:</p> <p>b) community:</p>	
<p># 2 Disability:</p> <p>Length of Diagnosis:</p> <p>Impact on:</p> <p>a) family:</p> <p>b) community:</p>	
<p># 4 Disability:</p> <p>Length of Diagnosis:</p> <p>Impact on:</p> <p>a) family:</p> <p>b) community:</p>	
<p># 5 Disability:</p> <p>Length of Diagnosis:</p> <p>Impact on:</p> <p>a) family:</p> <p>b) community:</p>	
<p># 6 Disability:</p> <p>Length of Diagnosis:</p> <p>Impact on:</p> <p>a) family:</p> <p>b) community:</p>	

## Q2 Continued

<p># 7 Disability:</p> <p>Length of Diagnosis:</p> <p>Impact on:</p> <p>a) family:</p> <p>b) community:</p>	
<p># 8 Disability:</p> <p>Length of Diagnosis:</p> <p>Impact on:</p> <p>a) family:</p> <p>b) community:</p>	
<p># 9 Disability:</p> <p>Length of Diagnosis:</p> <p>Impact on:</p> <p>a) family:</p> <p>b) community:</p>	
<p># 10 Disability:</p> <p>Length of Diagnosis:</p> <p>Impact on:</p> <p>a) family:</p> <p>b) community:</p>	

Q. 3

Brief Summary/Key Points

Notable Quotes

#1 Problem:

Solution:

#2 Problem:

Solution:

#3 Problem:

Solution:

#4 Problem:

Solution:

#5 Problem:

Solution:

#6 Problem:

Solution:

#7 Problem:

Solution:

#8 Problem: Solution:	
#9 Problem: Solution:	
#10 Problem: Solution:	



Q. 4	<u>Brief Summary/Key Points</u>	<u>Notable Quotes</u>
#1 Greatest Challenge:		
#2 Greatest Challenge:		
#3 Greatest Challenge:		
#4 Greatest Challenge:		
#5 Greatest Challenge:		
#6 Greatest Challenge:		
#7 Greatest Challenge:		
#8 Greatest Challenge:		
#9 Greatest Challenge:		
#10 Greatest Challenge:		

**Q. 5****Brief Summary/Key Points****Notable Quotes**

# 1 Where you go for support:

Types of support:

- a. friendship
- b. advice
- c. guidance
- d. access to information
- e. financial assistance
- f. medical services
- g. other \_\_\_\_\_

# 2 Where you go for support:

Types of support:

- a. friendship
- b. advice
- c. guidance
- d. access to information
- e. financial assistance
- f. medical services
- g. other \_\_\_\_\_

# 3 Where you go for support:

Types of support:

- a. friendship
- b. advice
- c. guidance
- d. access to information
- e. financial assistance
- f. medical services
- g. other \_\_\_\_\_

## Q 5 Continued

# 4 Where you go for support:

Types of support:

- a. friendship
- b. advice
- c. guidance
- d. access to information
- e. financial assistance
- f. medical services
- g. other \_\_\_\_\_

# 5 Where you go for support:

Types of support:

- a. friendship
- b. advice
- c. guidance
- d. access to information
- e. financial assistance
- f. medical services
- g. other \_\_\_\_\_

# 6 Where you go for support:

Types of support:

- a. friendship
- b. advice
- c. guidance
- d. access to information
- e. financial assistance
- f. medical services
- g. other \_\_\_\_\_

Q 5 Continued

<p># 7 Where you go for support:</p> <p>Types of support:</p> <p>a. friendship</p> <p>b. advice</p> <p>c. guidance</p> <p>d. access to information</p> <p>e. financial assistance</p> <p>f. medical services</p> <p>g. other _____</p>	
<p># 8 Where you go for support:</p> <p>Types of support:</p> <p>a. friendship</p> <p>b. advice</p> <p>c. guidance</p> <p>d. access to information</p> <p>e. financial assistance</p> <p>f. medical services</p> <p>g. other _____</p>	
<p># 9 Where you go for support:</p> <p>Types of support:</p> <p>a. friendship</p> <p>b. advice</p> <p>c. guidance</p> <p>d. access to information</p> <p>e. financial assistance</p> <p>f. medical services</p> <p>g. other _____</p>	

Q 5 Continued

<p># 10 Where you go for support:</p> <p>Types of support:</p> <p>a. friendship</p> <p>b. advice</p> <p>c. guidance</p> <p>d. access to information</p> <p>e. financial assistance</p> <p>f. medical services</p> <p>g. other _____</p>	
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**Q. 6**

**Brief Summary/Key Points**

**Notable Quotes**

# 1 Circumstance: Said or Done: Lesson Learned:	
# 2 Circumstance: Said or Done: Lesson Learned:	
# 3 Circumstance: Said or Done: Lesson Learned:	
# 4 Circumstance: Said or Done: Lesson Learned:	
# 5 Circumstance: Said or Done: Lesson Learned:	
# 6 Circumstance: Said or Done: Lesson Learned:	
# 7 Circumstance: Said or Done: Lesson Learned:	

**Q 6 Continued**

# 8 Circumstance:  
Said or Done:  
Lesson Learned:

# 9 Circumstance:  
Said or Done:  
Lesson Learned:

# 10 Circumstance:  
Said or Done:  
Lesson Learned:

**Q. 7****Brief Summary/Key Points****Notable Quotes**

# 1 Dream Network:

# 2 Dream Network:

# 3 Dream Network:

# 4 Dream Network:

# 5 Dream Network:

# 6 Dream Network:

# 7 Dream Network:

# 8 Dream Network:

# 9 Dream Network:

#10 Dream Network:

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**Brief Summary/Key Points**

**Notable Quotes**

**Q. 8**  
# 1 Who dialogue with:

# 2 Who dialogue with:

# 3 Who dialogue with:

# 4 Who dialogue with:

# 5 Who dialogue with:

# 6 Who dialogue with:

# 7 Who dialogue with:

# 8 Who dialogue with:

# 9 Who dialogue with:

# 10 Who dialogue with:

**Q. 9**

**Brief Summary/Key Points**

**Notable Quotes**

# 1 Single most important issue:	
# 2 Single most important issue:	
# 3 Single most important issue:	
# 4 Single most important issue:	
# 5 Single most important issue:	
# 6 Single most important issue:	
# 7 Single most important issue:	
# 8 Single most important issue:	
# 9 Single most important issue:	
#10 Single most important issue:	

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## APPENDIX N

Suggested Introduction Text:

**Welcome by Interviewer:**

"Good evening and welcome to our Focused Interview session. Thank you for joining our discussion regarding family support needs. My name is (Interviewer) and I will be facilitating this discussion on behalf of parents with children with disabilities, who serve as members of the North Dakota Family Involvement Subcommittee and the Family to Family Network Project at the University of North Dakota. We are seeing information about the support needs of families with children with disabilities. We have invited people to attend these sessions who represent children of different ages, disabilities and who are from different locations across the state of North Dakota. You were selected because you have expertise that is of particular interest to us. You all have children with disabilities, which influences your family's interactions and your involvement in the community. Having a child with a disability in the family unit may result in the need for additional support services and access to support networks, which may not be necessary in other family units. As a participant in this interview session, you will be representing other parents who have children with disabilities from your area and across the state.

Tonight we will be discussing family support needs. This includes all of the ways that you gain the necessary encouragement and support needed to cope with having a child with a disability in your family unit. **During our discussions, please note that there are no right or wrong answers but rather differing points of view and different types of support that family member's value. Please feel free to share your point of view even if it differs from what others have expressed.**

Before we begin, let me remind you of some of the ground rules.

**Tape Recording:**

Please speak up so that others may hear your comments.

Only one speaker should be talking at a time.

(We will be tape recording the session because we don't want to miss any of your comments. If several individuals are talking, the information on the tape will be unclear and some comments may be missed.)

**Confidentiality:**

We will be on a first name basis tonight, however, no names will be attached to any comments in our reports and you may be assured of complete confidentiality.

**Time Limit:**

Our session will last about an hour and a half and we will not be taking a formal break. The rest rooms are located (description of location). Please feel free to help yourself to coffee and cookies whenever you like.

**Name Cards:**

You all have name cards, which we would like to have you place in front of you to help us remember each other's names.

**Format of Interview:**

During the course of the session I will be asking nine different questions in sequential order. The questions are also printed on the wall chart. You will each have an opportunity to respond to each question. We'll have to limit responses due to our limited time. Although your responses will be recorded thoroughly by (Recorder), I will be using a wall chart to record key concepts or issues.

To get us started, find out some more about each other by going around the room and telling our names and where we live.

## APPENDIX O

## MEMORABLE QUOTES FROM FOCUS GROUP INTERVIEWS

"It's like, you know how your other kids kind of grow up and you have an empty house for a few hours to catch a breath, you don't really ever get those few hours to have some time alone."

"We can only do what the community allows or will open up to do."

"You can't just go out. Even at night sometimes I know my friends who have normal children, I shouldn't say that but for lack of a better word, even they go out for walk at nights when their children fall asleep and we have so much guilt."

"So you're just caught, cuz you need that respite but you feel bad because you know that they don't have their friends so they need their mom. They don't have buddies, they don't go to movies, they don't go to bowling alleys with their buddies, they just have you and then you're saying, 'oh I am really tired. If I don't sleep in this morning, I'm going to die.' You know."

"People tell me he can't walk, he'll walk. I mean, it may not be perfect, but he'll do it. You tell me he can't do something I'll push him till he will."

"You know when we look at difficulty in our home life, one of the big things is time. You know finding time for each other, finding time for yourselves, finding time to do things."

"The biggest challenge is being able to give him the life that he deserves."

"I think just everyday it's a challenge to get through the day and when you think about the future it's like, what's his life going to be like? How functional is he going to be? Will he stay out of trouble?"

"I still have this feeling like I don't know what my rights are, that's why I keep asking questions."

"My ideal system, a 1-800 number that I could dial that could answer every one of my questions."

"I'd love to see a statewide 1-800 number where you could call and say 'my kid's teacher gave me your number, my kid has these problems and has been diagnosed with this' and then the next day they'd put this packet in the mail to you about accessibility issues, about wheelchairs and elevators, school stuff."

"I have made my own community."

"Every transition has been difficult."

"Why is parent failure always the first one presumed?"

"My greatest challenge is just trying to be the parent that my child with a disability needs."

"My biggest challenge is to educate people that even though the child has a disability, they're normal inside, that they have the same wants and needs as everybody else."

## REFERENCES

1. Singer GHS, Powers LE. Families, Disability and Empowerment: Active Coping Skills and Strategies for Family Interventions. Baltimore, Md: Paul H. Brookes Pub Co; 1993:31.
2. Boukydis CF. Cited by: Singer GHS, Powers LE. The Importance of Parenting Networks. Paper presented at Parent Care Conference. Salt Lake City, Utah; October 1984.
3. Toombs M. Missouri Parent-to-parent Network: A Project to Determine Feasibility. Missouri Planning Council for Developmental Disabilities; April 1993.
4. Gallagher J, Beckman P, Cross A. Families of handicapped children: sources of stress and its amelioration. *Exceptional Children*. 1983;50:10-19.
5. Santelli B, Turnbull A, Lerner E, Marquis J. Parent-to-parent programs: a unique form of mutual support. *Infants and Young Children*. 1995;8(2):48-57.
6. Lieberman F. Clients of patients: families of children with developmental disabilities. *Child and Adolescent Social Work*. 1989;6:253-257.
7. Krauss M, Giele J. Services to families during three stages of a handicapped person's life. *Marriage and Family Review*. 1987;11:213-229.

8. Hartman AF, Radin MB, McConnell B. Parent-to-parent support: a critical component of health care services for families. *Issues in Comprehensive Pediatric Nursing*. 1992;15:55-67.
9. Dunst C, Trivette C, Cross A. Mediating influences of social support: personal, family and child outcomes. *American Journal of Mental Deficiency*. 1986;90:402-417.
10. Scott S, Doyle P. Parent-to-parent support. *Exceptional Parent*. 1984;15(1):15-22.
11. Santelli B, Turnbull A, Marquis J, Lerner E. Parent-to-parent programs: ongoing support for parents of young adults with special needs. *Journal of Vocational Rehabilitation*. 1993;3(2):25-37.
12. The Self-Help Source Book: Finding and Forming Mutual Aid Self-Help Groups. Denville, NJ: American Self-Help Clearinghouse; 1996.
13. Santelli B, Turnbull A, Sergeant J, Lerner E, Marquis J. Parent-to-parent programs: parent preferences for support. *Inf Young Children*. 1996;9:53062.
14. Santelli B, Turnbull A, Marquis J, Lerner E. Parent-to-parent programs: a resource for parents and professionals. *Journal of Early Intervention*. 1997;21:73-83.
15. Boukydis CF. An Overview of Parent Support Groups. Paper presented at: 4<sup>th</sup> Parent Care Conference; 1987; Philadelphia, Pa.



16. Santelli B, Squires S. Parent-to-parent Information Packet. Lawrence, Kan: University of Kansas, Beach Center of Families and Disability; 1995.
17. National Resources for Parent-to-parent. International Parent-to-parent Conference; 1998; Atlanta, Ga.
18. Research Summary Parent-to-parent National Survey Project, Beach Center. Kansas City, Kan: The University of Kansas; 1993.
19. Statewide Parent-to-parent Program Digest. International Parent-to-Parent Conference. Atlanta, Ga; 1998.
20. Singer GHS, Marquis J, Powers LE, et al. Consortium to evaluate parent-to-parent: pre-publication draft of a multi-site evaluation of parent-to-parent programs for parents of children with disabilities. Journal of Pediatric Psychology; in press.
21. Kagan S, Weissbourd B. Putting Families First. San Francisco, Calif: Jossey-Bass Pub; 1994.
22. Singer GHS, Powers LE. Families Disability and Empowerment. Baltimore, Md: Paul H. Brookes Pub Co; 1993.
23. North Dakota Interagency Coordinating Council Family Involvement Subcommittee, North Dakota Family-to-Family Network Planning Proposal; July 1996.